



1+Million Genomes WG-7 Industry Involvement

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1+MG/WG7: 21 nominated members from 16 signatory states

ArPharm

Institute of Applied Biotechnologies a.s.

Pharma Industry Finland

Healthtech Industry Finland

Università di Verona Borgo Trento

Faculty of Science, Dept. of Biotechnologies, University of Verona

Lithuanian University of Health Sciences Kauno klinikos Hospital

Vilnius University Hospital

BBMRI-NL

Vinnova

Investment and Development Agency

Trade association for the research-based pharmaceutical industry

Health Cluster Portugal

Luxembourg Institute of Health

Center for Genomics and Transcriptomics (CEGAT)

Biopeople, University of Copenhagen

Spanish Association of Bio companies (AseBio)

Ministry of Social Affairs

Association of the Pharmaceutical Industry in Norway (LMI)

Question for today:

- How can stakeholders help scale up and make the work of 1+MG/B1MG in data governance, data standards and technical infrastructural aspects sustainable?
- How can industry facilitate this process/ gaps industry can fill?

Original focus:

Industry involvement

- All details of the project were in a very early stage

Involvement of private industry, first steps:



- It was originally agreed with the Signatories that WG7 would not directly involve private organizations or industry as nominated experts, due to the sensitivities surrounding commercial issues of genomics.
 - However, what those sensitivities were, remain unclear.
 - Building trust and the trust framework is a big thematic issue, but where is trust lacking in terms of industry? In data processing? Is there a loss of trust in the industry actors?
- Involvement of private industry was approached by identifying the role of industry in genomics
 - Industry as a data user? WG7 wanted to expand this perception of industry.

Examples:



- Project support
 - pilot and implementation studies, provide expertise and experience, support health economic analyses, provide educational materials and training or genetic counselling
- Partners in scaling up the initiative
 - Project management support, advice and access to a network of experts to ensure we can identify gaps in infrastructure and successful scale up
 - Incl. supporting and leveraging global networks for standardization
- Data solutions provider
 - Develop and provide solutions and bioinformatics platforms
- Technology solutions provider
 - Providing f.ex. Sequencing and array technology, as well as reagents
- Scientific innovator
 - Develop and manufacture new innovative solutions to improve and enable genomic testing and analysis
- Data for research and development
 - With necessary checks in place, stringent consent and privacy measures, industry could also access the data to advance innovation

Industry needs and challenges - what's missing?

- An illustration of the genomics ecosystem in SCs and the EU

- Community
- Health hubs
- Corporates
- Accelerators and scale up
- Industry support
- Funding
- Hospitals and test labs
- Education
- Events

There is a clear need to add industry in the National Mirror Groups in each signatory country.

Disease specific industry involvement

- document relevant use cases for industry involvement in the 1+MG initiative covering rare disease, cancer, common/population-level diseases and COVID-19 and other emerging infectious diseases.
- This is an area for collaboration! WG7 could support the other working groups but would need to involve individual industry experts.
 - F.ex. assessing the impact of non-communicable diseases (NCDs) to healthcare systems
 - There is dramatic need for innovation in preventing NCDs
 - Industry can help deliver
- Problem: how do we find these industry reps in the different countries?

Going back to the question of today.....

- How can stakeholders help scale up and make the work of 1+MG/B1MG in data governance, data standards and technical infrastructural aspects sustainable?
- How can industry facilitate this process/ gaps industry can fill?

Are we asking the right questions?

Learnings and suggestions for consideration / 1



- Much effort is focused on establishing and scaling up the 1+MG infrastructure.
- But what is the value proposition for industry? There are no short term profits.
- The opportunities of the entire (digital) genomic ecosystem need to be made visible to industry and funders. What's in it for them?
 - Acceleration, international business opportunities, opportunity for scaleup, funding
 - Focus on establishing and supporting the developing ecosystem, rewards can be expected on many levels afterwards. What is the expected time span?
- We need examples of organizations which have invested in Europe. Why did they choose Europe? Why do they stay? Have we missed or lost some investments?
- What is the narrative? What is the success that we are building this infrastructure for?

Learnings and suggestions for consideration / 2



- The ecosystem has to be open to all newcomers as well.
- Less generic, more tailoring (f.ex. Disease specific data).
- Action point: we need to identify the services which we need to support use of genomic data and establishing & scaling up the infrastructure.
- Are we establishing an innovative policy regime? Is the legislative framework stable enough?

Joining or supporting a large scale genomics project such as the 1MG can be relatively high risk for industry!

- We need to show public commitment and support for involving industry.
- Mutually: industry should support the Signatory States in building public trust.



Thank you!

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