Introduction

Field specific ecosystem

Precision medicine has been defined as "an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person".

So far, medicine has mostly been working through "one-size-fits-all-treatments". While this approach works for many patients, it does not help everyone equally, as some of the most important drugs on the market are only effective on a relatively small percentage of them. Precision medicine aims at predicting which strategy fits best to a group of people or a single patient.

The characterisation of an individual's genetic background is possible thanks to the development of genome sequencing technologies. A major role is played by pioneering industries which develop faster, cheaper and smaller devices. As citizens become more eager to improve their quality of life, also beyond the treatment of a disease, more advances are expected to come. A transition from reactive to preventive medicine is under way, with a major shift in focus from diseases to well-being.

Precision medicine has thus the potential to revolutionise healthcare. But a new approach requires differently trained health professionals and a new type of relationship between doctors and patients.

Patients need to be made aware of how to understand complex information that will guide their choices among different options and to be granted the right to access their diagnostic data. Security, data handling and processing, medical devices to collect data, and mobile technologies are all fields in which the industry might play an important role.

Advancing precision medicine brings together stakeholders at the intersection of different domains. Universities are part of this groups as they are the site of basic and applied research in genomics, bioinformatics, and biochemistry, but also an important link between research and the clinic through university hospitals. In the private sector, pharmaceutical companies play a key role, alongside equipment producers (e.g. genome sequencing devices), software developers, and data storage companies. This industrial area also

expands to new types of technologies, like wearables, which are playing a more and more crucial role in tracking medically relevant data. Other companies build on these technological platforms to offer genetic testing and other services to doctors and hospitals. Bringing products and services to market requires capital, which brings public funding agencies, venture capitalists and start-up incubators into the picture. Guaranteeing patient safety and product quality involves regulators, including ethics commissions, that review the technological, ethical and legal basis for patient trials, product liability and data protection. While these organizations are fundamental in bringing precision medicine innovations to market, the demand is created by patients, medical professionals, and intermediaries. The latter encompass health insurances, professional associations and trade groups that mediate between demand and supply. Precision medicine relies on established medical professions in tandem with new or evolving ones, such as genetic counsellors or pharmacogenomics specialists. Patients are the key beneficiaries. They are represented by disease-specific advocacy groups. Patients also link wider aspects of society to precision medicine, particularly because the shift towards a participative approach to healthcare demands a proactive role of all citizens.

The present document, a SMART Map for the responsible advancement of Precision Medicine, contributes to addressing this scenario. It is the joint product of an inclusive process of co-design, involving representatives from relevant industries, research institutions, healthcare, the public sector, civil society, and patients' organisations.

The context of responsible research and innovation

The European Commission describes Responsible Research and Innovation (RRI) as an approach which "implies that societal actors (researchers, citizens, policy makers, business, third sector organisations, etc.) work together during the whole research and innovation process in order to better align both the process and its outcomes with the values, needs and expectations of society".

Demonstrating how responsible innovation can be implemented in an industrial context is an open task, as is providing evidence that responsible innovation is an effective approach to opening up of the innovation process to social actors, ensuring the quality of products and processes. The European Commission sees a need for an improved business governance that deeply embeds creativity, scalability, responsiveness, circularity and societal

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Project coordinator
prof. Francesco Lescai - Aarhus University
info@projectsmartmap.eu

engagement. To achieve this goal, it supports actions that aim to increase public-private partnership in the innovation process, to increase the social value and acceptability of innovation, and facilitate the emergence of new business models that embed sustainability and social responsibility throughout the entire business process.

It is in this context that SMART-map operates.

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