3.F. Round table: Implementing personalized prevention in the health care: proposal for a new framework

Organised by: Section of Public Health Genomics and the European Observatory on Policy and health Systems
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Extensive development in genomic medicine and related sciences are already providing opportunities for public health interventions to improve public health through personalized prevention (PP) programs. PP recognizes that people differ in their risk of disease and in their likely response to preventive programs. There is a large consensus that PP is a driver of innovation for research and health care, and also for the health care system and industry as a whole. The current scenario, however, see health care at a crossroad with financial pressures undermining the sustainability of the health systems. Expenditure increase due to demographic changes, greater patient expectation, and scientific and technological advances require new models of governance and new approaches.

The purpose of this workshop is to present and discuss with policy makers, researchers and educators, health service managers and advisers, a new framework to implement PP in the health care. The discussion will revolve around the role of genome-based and digital science and technologies in the development of future sustainable health systems. The framework will be illustrated in the context of the knowledge of the current scenario of the policies of public health genomics in the Member States, where existing, as reported in the forthcoming publication of the European Observatory.

Emphasis will be given to the role of education of professionals, and to a 'proper' citizen empowerment.

The added value of the workshop is to discuss on the future path of the prevention in the new context of personalized medicine, and how this should integrate the currently available approaches in a sustainable way.

Key messages

- A sustainable health care require new paradigms in prevention
- A personalized approach to prevention that combines 'omics' information and the use of digital technologies requires new policy frameworks for a proper implementation in the health care

A framework for new practice in public health genomics

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Sustainable health systems will require a shift from treatment of established disease to early diagnosis and prevention and the empowerment of citizens to take greater responsibility for their health. New biomedical and digital science and technologies, alongside the encouragement of societal changes that support individualism can play an important role tailoring interventions to an individual's biology and forming the basis for personalised prevention. At whole population level this requires understanding of the combined effects of genetic and environmental determinants of disease risk and the targeting of interventions to subsets of the population and the use of genomic markers for early detection of disease or the reduction of disease progression. On a wider basis, public health leaders have a responsibility to help catalyse change in the organisation of health services and public policy to ensure that genomic and other technologies are used to best effect. Clinical and laboratory services may have to be reconfigured with centralisation of expensive technologies and expertise; point of care diagnostics may be developed and all must be integrated with greater use of digital technologies such as wireless sensors, new imaging and mobile connectivity. The move to empower citizens will mean that they will demand and use access to information about themselves with implications for electronic health records, biobanking, data storage and sharing. And finally societies will need to address the ethical and political implications of personalised prevention considering the balance between solidarity and autonomy, privacy and datasharing, potential new inequalities, tolerance of diversity in interventions offered to citizens and the regulation of the commercial sector producing devices and diagnostics, direct to consumer products and services. These elements form a framework for new practice in public health genomics which can have a major impact on health and healthcare.

Public Health Genomics: moving towards the implementation of dedicated policies in Europe

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The application of genomics in health care has the potential to reduce the burden of disease and improve population health. This will be most successful if it is developed as a natural extension to and a complement of traditional public health approaches. A proper integration of genomics into health care, however, requires that health system policy-makers, stakeholders and knowledge brokers are aware of the potentials and limits of the use of genomics in disease risk prediction, diagnosis and treatment, so that they can provide the necessary policy response. Given the complexity of the issue to be addressed, policy responses need to be multidimensional and involving multiple actors, health professionals, decision makers in health, academics, patients and citizens. Public health professionals and those who are responsible for

designing health systems have a duty to engage and facilitate the implementation process in order to ensure a proper balance, and to make policy makers aware of its relevance. Education and health literacy of the professionals, citizens, policymakers and other stakeholders is an important issues for proper implementing genomic medicine. These issues have been discussed during a meeting of the 28 Chief Medical Officers of the Ministry of Health of the Member States, who participated a convened in Rome in Oct, 2014 to discuss on the European policies of public health genomics, October. The meeting was organized by the Italian Ministry of Health during the Italian Presidency of the Council of European Union, and participated by the European Observatory. As a follow up of this meeting, the European Observatory is elaborating a policy summary on the policies of public health genomics in Europe, that will further incorporate elements of the framework discussed by Hilary Burton in this round table.

Ethical Challenges of Big Data in Public Health

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Digital epidemiology, also referred to as digital disease detection (DDD), is motivated by the same objectives as traditional epidemiology. However, DDD focuses on electronic data sources that emerged with the advent of information technology. It draws on the explosive growth in mobile devices, and online sharing platforms, which constantly generate vast amounts of data containing health related information, even though they are not always collected with public health as an objective. Furthermore, this novel approach builds on the idea that information relevant to public health is now increasingly generated directly by the population through their use of online services, without their necessarily having engaged with the health care system. By utilizing global real-time data, DDD promises accelerated disease outbreak detection, and examples of this enhanced timeliness in detection have already been reported in the literature. The emergence of DDD promises tangible global public health benefits, but these are accompanied by significant ethical challenges. While some of the challenges are inherent to public health practice and are only accentuated by the use of digital tools, others are specific to this approach and largely unprecedented. They span a wide spectrum, ranging from risks to individual rights, such as privacy and concerns about autonomy, to individuals' obligations to contribute to the common good and the demands of transparency and trust. We have grouped these concerns under the headings of context sensitivity, nexus of ethics and methodology, and bootstrapping legitimacy. It is vital that engagement with these challenges comes to be seen as part of the development of DDD itself, not as some extrinsic constraint. We intend this paper to be a contribution to the development of a more comprehensive and concrete ethical framework for DDD, one that will enable DDD to find an ethical pathway to realizing its great potential for public health.

The role of innovation in health care sustainability

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The complexity of 'omics sciences and related applications requires a governance from the health care systems.
In Italy, first Country in Europe, the National Prevention plan foresees since 2012 the macro-area of personalized medicine, along with primary/secondary/tertiary traditional prevention areas. In 2013, to concretely realize the personalized prevention plan, the State-Region conference approved and published the national guidance of public health genomics, and currently the action plan is under development. The topic of innovation in health care, however, has not been addressed in a multi-dimensional scale, so far.
Innovation in the 'omics science has currently two main goals:

- Knowledge generation (including translational/applied research);
- capacity building through education of the future health care professionals;

Knowledge generation in health care mainly consists in:

- use of Health Technology Assessment in the newly available 'omics applications that can feed guidelines on preventive services;
- Computational medicine;

Capacity building of health care professionals mainly consist:

- educating the physicians and related relevant actors (e.g., biologists working in laboratories, nurses, pharmacists) in understanding and handling the complexity of the information;
- set up new paths for physicians within the resident school in public health and preventive medicine in order to make them working as clinician of the personalized prevention;
- Training of a workforce of bioinformatics
- Set up innovative tools for distance learning training of 'omics science of general practitioners.

Personalized pREvention of Chronic Diseases: the PRECeDI H2020 project

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The aim of the Personalized pREvention of Chronic DIseases consortium (PRECeDI) is to provide high-quality, multi-disciplinary knowledge through training and research in Personalized Medicine (PM), with specific reference to prevention of chronic diseases. There is a large consensus that PM is a driver of innovation for research and health care, and also for the health care system and industry as a whole. In order to harness the potential of this new concept, the PRECeDI consortium provides a cohesive framework for training staff from academic and non-academic (NA) institutions on research topics related to PM, with specific reference to the prevention of chronic diseases where there is a lack of substantial evidence, though the potential is huge. The acquisition of skills from staff will come from dedicated secondments aimed at training on research topics not available at the home institutions, and attendance to courses, workshops, seminars, conferences. The goal of secondment is to enable staff to make informed decisions for appropriately serve health care systems, new biotech industries and policy makers at the dawn of the post-genomic era. PRECeDI is a multidisciplinary group of institutions working on different facets of PM, from basic research, to economic evaluations, health service organization, and ethical, social, and policy issues. The consortium is embedded in existing cooperation structures, such as the PerMed project and the Erasmus Mundus ERAWEB II program, with additional leading SMEs in Europe and Canada as beneficiaries. The consortium consists of 11 partners, of which 7 are academic institutions and 4 NA, including 2 SMEs. During 4-years, 30 researchers will be seconded to 11 institutions, where researchers will be supported by a team of leading EU scientists in PM related disciplines. In the long run, PRECeDI will foster the integration of PM in the field of prevention, thus contributing to better health for Europe's citizen.