

Paths to Precision Health: Act Now

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It is a truism that pressures are being felt by health systems the world over. Demographic trends, technological advances and the expectations of citizens all act to widen the gap between available resources and the requirements for health care. Some optimism can be found in the advances from information technologies, new diagnostics, therapeutics, genomics and other life sciences under the rubric of *precision medicine* that are seen as key parts of a novel system of health care that will result in better health outcomes for all citizens. But the current evolutionary pace of change is not likely to get us there.

We need to take several revolutionary “disruptive leaps”.

Policy makers must act now to undertake this transformation to make our health systems fit for the future. Health systems must be able to respond to and cope with both today’s Zika epidemic and tomorrow’s ageing population. This will require a radical reorientation that advocates greater personal participation in the health system, places the citizen at its centre, and looks to greater emphasis on disease prevention and on health.

The activation of Article 27 of the 1948 **Universal Declaration on Human Rights** which upholds the right of citizens to benefit from advances in science and its applications is one such leap. But additionally we must do four other things.

1. ***Free the Data.***

Researchers need more data to advance knowledge and to support translational medicine. Governments need evidence to inform policy while commercial companies require predictable data to plan for R &D investment. The data needed to transform our personal health is dependent on allowing researchers access to health data and the ability to share widely. We need data from all sources, those collected by ourselves, those in our medical records and those from our environment. Freeing of data is realistic only if based on the principle of reciprocity, where data custodians are confident that removing barriers will not have unintended consequences, and data contributors are willing to allow breaches in return for hoped for benefits. But “freed data” is not the main goal; rather it must be the creation of a minimum

data set of clinical and research health data and of population reference databases, integrated in real time, and shared across jurisdictions. Sharing should be the norm.

2. *Engage the Citizen.*

Current models of citizen engagement emphasize voting, patient advocacy and various social science models of public participation such as polling or focus groups. More innovation is needed. It should become the norm for citizens to contribute their data and to access the information they need to make informed decisions within a more transparent health system. It should be considered a public responsibility to make such a contribution for the public good as an act of civic solidarity or benevolence.

We imagine the inclusion of contributed data from cradle to grave. Engagement should involve more than speaking out and speaking up. The contribution of one's medical records and previously collected bio-specimens to the public trust would have a multiplier effect that would 'pay forward' and serve as an investment in a country's path to health; as valuable as organ donation. Contributed in real time into a dynamic, non-linear health learning system, the best aspects of the clinical pathway model would be combined with an engineering model for on-going evaluation, failure analysis, and re-design. The use of social media will be a game changer as more people (perhaps especially millennials) interact with these technologies as their principal form of civic action.

3. *Break Down Silos.*

Access to data requires lowering barriers to collaboration and new ways of bringing together research, clinical care and population health activities. We must recognise individuals as members of different subpopulations at different times with different levels of risk or resistance to disease. The barriers between a traditional public health model predicated on social determinants and a model of clinical care based on biomedical science must be eliminated. Cross-disciplinary training, with appropriate incentives and certification, should be the means to bring them together. We must move to a system where research is care, and care is research. The blurring of these boundaries will be a *sine qua non* for the ethical standards of future professional practice and offer paths to the future of precision health for all citizens.

4. *Actively Develop Leaders*

These proposals will be mere aspirations if they cannot be translated into reality. To do so requires leadership and in particular a high level of commitment that transcends the 3 to 5 yearly horizons of most politicians. In our framework for precision health five common themes have emerged that capture its essence: visioning; creating a culture of shared values; strategy forming and implementation; empowerment of people; influence, motivation and inspiration. Leadership is essential if we are to shape and change culture; management and administration can only act within the context of that culture.

This statement is from a workshop comprising participants from the UK, Italy, Belgium, Hungary, Canada and the United States, brought together on 5 to 6 October 2016. The workshop sought to discuss the future of health systems in the light of genomics and other biological and digital technologies. The workshop was convened by the signatories below, speaking on their own behalf, and was hosted by the PHG Foundation.

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