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Public Health Pharmacogenomics and the Design Principles for Global Public Goods – Moving Genomics to Responsible Innovation

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“Evidence in the clinical care context differs from evidence in the public health and health policy domains. It is often difficult to apply rigid hierarchies of evidence to public health policy.”

Tikki Pang [1]

“Pharmacogenomics and personalized medicine knowledge cannot be siloed into a pure and narrow technology lens alone. The field’s ontology requires a nuanced understanding of the complex linkages between the science, technology, society, and politics ecosystem and therefore must be situated within a broader framework.”

Edward S. Dove [2]

“The trend has been to use data derived from African populations to build research programmes and enhance individual careers in more affluent communities with little or no consideration for the populations from which this material was derived.”

Jantina de Vries and Michael Pepper [3]

1. A POPULATION FOCUS FOR GENOMICS, PERSONALIZED MEDICINE AND GLOBAL SOCIETY

Current Pharmacogenomics and Personalized Medicine (CPPM) was launched in 2008 to respond to knowledge,

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policy and biotechnology governance gaps at the unique intersection of personalized medicine, genomics, public health and social studies of knowledge-based innovation. Distinct from traditional discovery science characterized by a “first hypothesize-then-experiment” method of scientific inquiry, this nascent field of public health pharmacogenomics is richly informed by CPPM scholarship that recognizes the new dual reconfiguration of 21st-century data-intensive omics science, blending infrastructure science and discovery science. Importantly, CPPM addresses novel diagnostics and responsible personalized medicine applications both in developing and developed countries. This is crucial for global capacity building, as developing countries may

lack the resources, expertise and sound regulation for pharmacogenomics; this may result in premature buy-in for novel biotechnologies without adequate alignment with local public health priorities and societal values [3, 4].

The journal aims to strike the right balance to catalyze the transition of pharmacogenomics and personalized medicine discoveries to practice, while preventing the premature translation of candidate applications [5-7]. Finally, the journal integrates molecular and clinical investigation with public policy and social studies of biotechnology, which collectively shape the postgenomics personalized medicine innovation trajectory.

2. LOOKING BEYOND THE LABORATORY SPACE: RESPONSIBLE INNOVATION

“Responsible innovation” is an emerging concept that CPPM scholars investigate, and is closely linked to public health pharmacogenomics. For innovation to be responsible, the scientific design space must involve more than traditional experts. It must involve a broad array of experienced, engaged and enthusiastic members of the public, such as citizen scholars, patients, policymakers and other knowledge end-users [5-10]. This “opening up” of the hitherto cloistered scientific design space produces scientific knowledge that is closely embedded with societal values, the public interest and end-user priorities and thus, becomes socially robust and sustainable.

Just as public health pharmacogenomic needs input from a broader, large range of publics, so too does it require access to large information databases and adequate knowledge translation platforms that facilitate knowledge synthesis and dissemination across experts and publics. The powerful scope of this field will be fully realized once genomic population-based studies can be effectively linked to population-based health administrative databases, electronic health records, and nutrition and lifestyle data. This has significant societal, legal and ethical implications, in terms of confidentiality and privacy of individuals contributing genomic data, not to mention the new ways of understanding these constructs in the age of post-genomics personalized medicine [11]. This will require profound deliberation and input from those involved in policy development. As it has done for the last five years, CPPM will continue to lead the way in co-creating and disseminating policy relevant scientific advances to sustain public trust in pharmacogenomics and public health.

Public health pharmacogenomics also offers the promise to prevent research waste, which remains a serious problem in the health domain. For example, a scoping analysis of 344 studies in health and allied sciences addressing patients’, clinicians’ and researchers’ priorities for research, found that only nine considered the extent to which questions posed by researchers matched questions of relevance to patients and clinicians [12]. Furthermore, translation of pharmacogenomics into the clinic remains a challenge, especially in low and middle income countries that can benefit much from effective and safe therapeutic regimes [13].

CPPM’s focus on public health pharmacogenomics is aligned with integrated, responsible innovation, knowledge

co-production and benefit-sharing by scientists, technology designers, communities and other producers or consumers of knowledge. As noted earlier by Dove in this journal [2], this in part reflects the journal’s commitment to horizontalization of knowledge co-production: it is not a question of the contributors’ age, gender, geographical location, perceived prestige of authors’ institutional affiliation, maiden language, individual social capital or economic power, but rather one of original, reasoned ideas and scholarship. We posit that a good amount of research waste can be eliminated if researchers and patients, participants and publics communicated with, rather than past, one another and consider viewpoints from all peoples and places, especially given the often serendipitous nature of scientific and technological discovery and development. Ultimately, such nonassuming horizontal approach to knowledge co-production helps create an open commons that is self-corrective and self-calibrating against biases, entrenched politics and disciplinary or epistemic “knowledge tribes” created by human kinds, and embedded in human positivist inquiry, be it in natural sciences, social sciences or humanities [4, 9].

3. DESIGN PRINCIPLES FOR GLOBAL PUBLIC GOODS

We have started the current socio-technical analysis of the post-genomics personalized medicine landscape with quotes from scholars in global public health and social studies of biotechnology and innovation, including Tikki Pang, the lead writer of the World Health Report 2012. Pang has recently suggested to us that the future developers and users of diagnostics for health interventions (theranostics) to be cognizant of the “design principles” for global public goods (GPGs), of which public health pharmacogenomics is a good example. These principles were outlined by Elinor Ostrom, Nobel Laureate in Economic Sciences in 2009 (Table 1, with modifications by Pang) [14, 15]. CPPM readers are encouraged to read the seminal works on the governance of the commons and institutional diversity by Ostrom [15, 16], and the ways in which these can impact behavior in society, including our 21st century knowledge society [8] that is being shaped by globalization of genomics and personalized medicine [5, 11, 13].

4. WHAT IS NEXT FOR PUBLIC HEALTH PHARMACOGENOMICS?

We are situating this first issue of the new year, and reaffirming the commitment of CPPM, to address the needs of the personalized medicine knowledge society [8, 17-22]. We are also commencing the new year with an expanded, globally inclusive, distributed and transdisciplinary international editorial board. CPPM senior editorial leadership will transition and evolve in the coming months to further accelerate this progressive vision that has brought to light cutting edge research, and transformative ideas in pharmacogenomics and personalized medicine over the past five years by leading scholars from all parts of the globe (see, for example, [13, 21-24]). In this inclusive spirit, we welcome your enthusiastic contributions of manuscripts for peer review in 2013 and beyond.

Table 1. Design principles for global public goods and the nascent field of public health pharmacogenomics.

- Clearly defined beneficiary of success;
- Convergence between success and environmental conditions is necessary;
- Contributions necessary to develop and use common resources should be monitored by individuals who developed and use the GPGs;
- Dialogue and discourse mechanisms should be available;
- Governance systems are organized in nested enterprises and each organization must conform to larger systems;
- Individuals affected by GPGs should have a voice in modifying the developmental pathways; and
- Individuals producing GPGs should have the ability to devise their own ways of achieving ends.

CONFLICT OF INTEREST

The author(s) confirm that this article content has no conflict of interest.

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ABBREVIATIONS

CPPM = Current Pharmacogenomics and Personalized Medicine

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