Personalised healthcare: bringing the future into focus

Final report, April 2017

Alison Hall and Leila Luheshi

Signatories: Prof. Bartha Maria Knoppers, Dr Eric Meslin, Prof. Walter Ricciardi, Dr Ron Zimmern

Contents

1.   Introduction

Between 4-7 October 2016, a group of invited international experts in health, public policy, public health, law and ethics assembled at Ickworth House, (Suffolk, UK) for a meeting entitled *Personalised healthcare: bringing the future into focus*. The meeting was convened by Prof. Walter Ricciardi, Dr Eric Meslin, Prof. Bartha Knoppers and Dr Ron Zimmern. Their goal in arranging the meeting was to encourage open and wide ranging discussions about the future of health and healthcare, looking at least 15-20 years into the future. In particular the meeting considered the greater personalisation of healthcare, the benefits and consequences that might accompany such a radical shift in the way in which we achieve better health, and some of the steps that policy makers and practitioners would need to take to realise its potential.

This report presents a summary of the wide ranging discussions that took place at this meeting. It is divided into two parts. The first part captures some of the elements of a more personalised health system and the benefits and limitations associated with such a system that were discussed by the delegates on Day 1. The second part summarises the key themes that emerged from our attempts to address these benefits and limitations.

2. Imagining future health

2.1 What could personalised healthcare look like?

At the outset of the meeting the delegates considered what the key features and attributes of a more personalised approach to health might be. These are summarised in the graphic below.
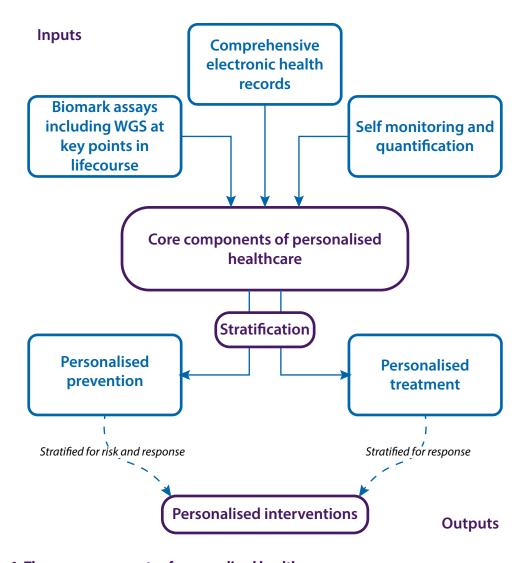
Inputs

```
Biomark assays            Comprehensive
including WGS at           electronic health          Self monitoring and
key points in             records                     quantification
lifecourse

                    Core components of personalised
                    healthcare

                          Stratification

Personalised                                          Personalised
prevention                                            treatment

Stratified for risk and response        Stratified for response

                    Personalised interventions

                                                      Outputs
```

Fig. 1: The core components of personalised healthcare
The components can be considered as a number of inputs and outputs comprising a system that achieves better health for individuals, and populations, through delivering more effective preventive and therapeutic interventions. The inputs are the multiple sources of data, and knowledge abstracted from these data, that will be accrued both by healthcare providers and by citizens themselves. The outputs will be the stratification of populations (perhaps ultimately with an n of 1) on the basis of their risk of particular diseases and / or their responsiveness to particular therapeutic interventions. The hypothesis underlying the construction of such a system being that targeting interventions to groups or individuals who are most likely to be responsive to those interventions could enable significant improvements in health compared to current 'one size fits all' approaches to preventive and clinical healthcare.

3. What are the potential benefits and challenges of personalised healthcare?

3.1 Potential benefits

Delegates then proceeded to discuss the potential benefits of moving towards a more personalised approach to achieving better health. Those suggested included:

» **Clinical practice**

- Improved confidence in clinical decision making

- Bridging the intuitive personalisation of medical practice with evidence based medicine

- Rational reclassification of disease

» **Patient benefits**

- Improved health outcomes

- Optimisation of the benefit / harm ratio for interventions at an individual level by:

- Reducing incorrect diagnosis or unnecessary interventions

    - *Avoiding pharmacotoxicity and other iatrogenic harm*

- Enhanced personal autonomy

    - *Improved diagnostic knowledge for patients*

    - *Integration of personal values in decision making*

- Empowering informed decision making

- Greater customization of services for individuals

» **A more effective and efficient health system**

- Greater predictability of future health enabling more effective prevention

- Increased effectiveness and efficiency of interventions through targeting to more responsive subpopulations / individuals

- Cost savings

- Enabling more effective and efficient interactions between health systems and industries

» **Social benefits**

- Normalisation of genetics for citizens

- Bypassing the challenge of health illiteracy

- A rational basis for the concept of 'equivalence in difference'

- Empowerment of patients to build communities to take action and control of their health

- More inclusive and equitable distribution of health benefits

3.2   Potential challenges

While there are many foreseeable (albeit uncertain) benefits associated with moving towards personalisation in health, the delegates also discussed in great depth many of the potential barriers, limitations and negative consequences that could be anticipated, and which policy makers might wish to seek to mitigate.

These included:

»   **Gaps in knowledge and evidence base**

  - Lack of scientific knowledge required to truly 'individualise' risk rather than simply defining sub populations at risk

  - Lack of professional knowledge and understanding could limit implementation

  - Lack of knowledge and understanding could affect acceptability to policy makers and citizens

»   **Reassigning social and personal responsibility**

  - Relocation of responsibility to vulnerable individuals

  - Genomic information may not empower citizens or enable rebalancing of the power relationship with physicians

  - Risk of developing a link between genetic risk, social responsibility and reproductive choice

»   **Personal and social attitudes to health**

  - Creating a population of 'worried well'

  - Blurring health and wellness

  - Exacerbating the conflation of need and demand

  - Information overload leading to disengagement or desensitisation

  - Depersonalisation occurring through reducing a patient to the sum of their data

  - Pervasive genetic illiteracy across all sectors

  - Negative impacts on family relationships and behaviour

»   **Policy making challenges**

  - Difficult to generalise experience or approach across different diseases, populations and technologies – policy needs stratifying too

  - Difficulty of integrating policy across disciplines required for complex, personalised care

  - Difficult and undesirable to legislate around personal reproductive choice

  - Dependence on improved leadership from multiple sectors: politicians, scientists, clinicians and industrialists

  - Tendency to 'bolt on' innovations, rather than transforming services; complexity and inefficiency increase

  - Ineffective dialogues between policy makers and politicians

» **Equity and discrimination**

- Inequity increases both locally and globally

- Potential to increase discrimination

» **Health system challenges**

- Lack of infrastructure and co-ordination around implementation research and policy making

- Lack of resources for training of workforce

- Significant lack of 'Health Technology Assessment' type evidence

- Need to balance size of population subgroups against cost of greater numbers of strata to be differentiated

4.   Emerging themes and concepts

Commentators have characterised a number of different visions of the future of healthcare in terms of the predominant drivers, extent of government involvement and likely catalysts for change. For example, a report from the World Economic Forum identified three scenarios:

» **Health Incorporated: as governments cut back on public services, new products and services are provided by corporations underpinned by a sense of conditional solidarity**

» **New Social Contract: governments drive health system efficiency and regulate organisations and individuals in pursuit of healthy living**

» **Super Empowered Individuals: citizens use health products and services provided by a competitive commercial sector to manage their own health. Governments attempt to address these consequences**[1]

There was agreement that none of these scenarios form a comprehensive or realistic vision of the future. Instead, constructing this vision will require a combination of incremental learning and more radical transformational approaches to meet both the foreseeable and novel challenges likely to be generated by personalised healthcare.

Section 3 of this report captured at a high level the very wide range of potential challenges and opportunities arising from the development of a more personalised approach to healthcare. However, over the two days of the meeting a number of recurring themes emerged as priorities to be addressed by all those involved in optimizing the health of citizens, not least citizens themselves. We have categorised these key themes for the purposes of this report into either 'Limitations to effective personalisation of healthcare' or 'pre-requisites for radical change in healthcare'.

4.1   Limitations to effective personalisation of healthcare

Increased personalisation is associated with a set of challenges which must be addressed if the potential benefits are to outweigh the potential burdens.

4.1.1   Personalisation – are we there yet?

Scientific and clinical research have significantly advanced our ability to more precisely define and even re-classify diseases. There have also been corresponding advances in stratifying patients into sub-groups on the basis of their likelihood of responding to a given treatment, and in stratifying otherwise healthy citizens on the basis of their future risk of disease. However, a significant gap remains between the delivery of stratification – which is seen as within the grasp of our current health systems - and 'true' personalisation, which is viewed as a still distant future prospect. The latter implies a level of precision that seeks to treat each citizen as a truly unique individual, as opposed to a member of a group (of potentially variable size) with whom they share some common health-related characteristics. Our current levels of knowledge and understanding of the variation and interplay between biological and social determinants of health and disease between individuals precludes such 'individualisation' of healthcare.

Personalisation also implies an approach to health that truly takes account of personal values and preferences, and places the person at the centre of their own care. While these attributes of a future health system are desirable, it remains to be determined how they can be developed in ways that are sustainable, equitable and effective. It is anticipated that personalisation will depend on a greater diversity of healthcare providers, providing a wider menu of care options and a step change in the capacity of citizens to undertake 'self-care'. It is also likely that emphasising personal preferences and values will drive an expectation that health systems will fulfil both 'wants' as well as what the system objectively defines as 'needs', potentially placing greater burdens on the resources of such systems.

---

1.   Sustainable Health Systems: Visions, Strategies, Critical Uncertainties and Scenarios. World Economic Forum in collaboration with McKinsey & Company, (2013).

4.1.2 Overdiagnosis

Increased monitoring of individuals through personalised approaches increases the potential for overdiagnosis. This may follow either from the identification of disease risk or the early detection of disease before it is clinically apparent, and essentially attaches the label of disease (and the burden of prevention or treatment) on an individual who was never going to experience clinically relevant disease. Although disease risk or the diagnosis of disease is experienced at the level of the individual (and may be deeply subjective), overdiagnosis can only be known for the individual in retrospect, and can only be measured at a population level. The potential for overdiagnosis raises questions about the semantics of 'health' and 'disease' and challenging societal questions about the potential benefits and harms of early detection and how the balance of these might be optimised. Opinions vary as to how much governments and health organisations should take responsibility for offering screening and advising of future risks of ill-health, and how much these should be left to individuals to decide. Those individuals who seek greater amounts of personal risk information might chose to access screening via commercial providers, but there was general agreement that such individuals should understand potential limitations in the utility of the information and the greater uncertainties involved.

The complexity of risk prediction and the need to take account of multiple effects (including protective variants) means that there will be challenges identifying the significance of the results that are generated, whilst maintaining trust in health and regulatory / governance systems and controlling costs. Looking further ahead, this may well involve difficult judgments about what constitutes an 'adverse state' where individuals differ along a continuum (such as with cognition, learning disability etc.). These differences are likely to have most traction (and potential for harm) where they coincide with social, ethnic, geographic or cultural groupings. Systematic, transparent approaches are needed, especially if there is state involvement in screening / testing or public funds are involved. Strategies for individuals to deal with their own risks might include people deciding what information they would not want to know, given that the 'signal to noise' ratio will decrease if the threshold for diagnosis is lowered.

4.1.3 Achieving equity in health – balancing demand and need in an era of more personalised healthcare

Some of the beneficial features of personalised medicine - that it is largely consumer led, and facilitated by a raft of novel technologies including m-health and social media - may, perversely, also act as limitations. Access to technologies may be inequitable. Those who are able to access personalised medicine may experience positive outcomes, but conversely, limited access to technologies may drive negative outcomes. In particular, 'demography is destiny' with younger people seemingly more open to potential benefits of personalised approaches, and less constrained by actual or perceived limitations. Conversely, the aging population or those with complex health needs may be less able to benefit from personalised approaches. Since linkage of different datasets is key to achieving effective personalisation, members of the population who are already disenfranchised (and likely to be the most needy) are likely to be excluded.

Empowering patients and consumers to proactively seek personalised healthcare is insufficient: in order to ensure equitable access - supportive policies and social structures are needed. In most countries, existing hierarchies and structures focus on treating acute ill health and disease. In order to optimise personalised approaches, it may be beneficial to create wellness systems that can focus on the potential for personalised prevention. Some countries (e.g. Taiwan) have developed integrated processes for recording lifestyle and environmental data and linking this with drug prescribing, drug side effects and hospital based care. Recording weight-loss data by institution / building or factory has been effective in demonstrating the impact of such programmes and could allow more systematic account to be taken of behavioural factors. However such programmes, could be regarded as potentially coercive, and as limiting personal autonomy: in many countries such data integration might not be tolerated. Nevertheless these examples demonstrate the potential impact that integrated approaches could have in health promotion.

Where personalised prevention is linked with issues of reproductive choice, questions of social responsibility for citizens and the state become extremely sensitive and may be highly charged, and the most responsible and pragmatic approach might be for governments to 'stand back' until conclusive evidence about their clinical utility becomes available. But considering the implications, public discussion and consultation on the socio-economic implications, as well as the need to prepare more anticipatory governance frameworks, would be a more responsible route.

4.2 Prerequisites for radical change in healthcare

For personalised approaches to be successful, a radical set of actions is likely to be required:

4.2.1 Achieving better genetic literacy for professionals and for publics

Effective personalisation will rely upon better genetic literacy for consumers and their families and for healthcare professionals. This can be achieved through increased education and training of professionals in order to achieve improved public understanding. Whilst the UK 100,000 Genomes Project provides a national test-bed to explore these issues in the short-term, the challenge in the longer term is to integrate and embed genomics within care. This should have the effect of reducing the public perception that genomics is associated with discrimination and therefore that genomic data deserves special protection. Increased precision of diagnosis, treatment and outcomes is likely to improve the health literacy of individual patients / consumers, but if it is to work well, implementing translational medicine needs to be iterative so that patient experience informs the care of subsequent patients as part of a learning healthcare system.

4.2.2 Retaining humanity and community in health and care

Since some personalised approaches utilise alternate forms of communication between citizens and patients and health professionals and systems and less direct contact, there are concerns that this might change the nature of the relationship between the two groups. It is important that there is still scope for the 'humane delivery of healthcare' whereby the intuition of the healthcare professional based on face-to-face encounters can still be expressed when this takes place within a reformed healthcare system. Personalised approaches might enable citizens to have greater determination over the values that are expressed within value-based health systems even if some aspects are depersonalised, but an underlying 'community structure' will be needed. Maintaining trustworthiness and quality could be facilitated through use of third-sector intermediaries and / or advocates of care.

4.2.3 Improved governance, consent and trust in healthcare

A number of changes are transforming the value of data: the enrichment of data to information and knowledge increases their utility, facilitated by improved technologies for data acquisition, storage, interrogation and linkage. New information can help empower individuals to better manage a chronic condition and make superior choices when they require care, but without a comparator, it is difficult to understand the significance of these data. However, the ability of healthcare systems to deliver care will be challenged by broader considerations around ownership and management of data. Enabling increased data processing requires commensurate regulatory responses: consent processes are evolving to include dynamic forms of consent, and there is an increased focus on governance. Other challenges include novel forms of hybrid clinician-researcher activity. There are a variety of regulatory responses which could be explored: recognition of a latent human right already enshrined in Article 27 of the 1948 Universal Declaration of Human Rights[2], which provides that all citizens should share in scientific advancement and its benefits, might imply that citizens would be receptive to the systematic collection of a minimal data set from all individuals; the European General Data Protection Regulation allows for Data Protection Boards to authorise Codes of Conduct, which might facilitate more harmonised approaches to be developed.

2   Universal Declaration of Human Rights. United Nations, (1948).

There is a need to move away from an assumption of 'hypothetical privacy' in which individuals 'own' their data towards a model in which healthcare systems are regarded as stewards of data. Intellectual property claims over products and data may limit potential data uses unless national and international collaborations occur at the precompetitive pre-emptive stage. Formalising reciprocity via novel intellectual property approaches also ensures that benefit flows into the system and may be advantageous.

4.2.4   Feeding and harnessing the data-knowledge cycle for better health

The development of personalised healthcare remains contingent on significant data acquisition and timely analysis to determine the most appropriate basis on which to tailor health optimisation for individuals. The democratisation of access to the means of data generation, through consumer health devices, social media and internet use, and direct to consumer bioanalysis (genomic, epigenomic, microbiome etc.) necessitates the development of ways to aggregate this data, along with more 'traditional' sources of health data generated during citizen encounters with healthcare professionals i.e. electronic patient records in primary and hospital care, and existing biobanks. Data aggregation with other administrative and environmental data that reflect the physical and social environment within which a citizen lives (and which has a profound effect on their health) could also have potential benefit. This is an enormous technical challenge given the diversity of information systems used to generate and record this data and their often poor interoperability.

It also presents an enormous regulatory, ethical and legal challenge to disentangle ownership and exploitation (IP) rights over this data, as well as collective and individual attitudes as to how it should be used, by whom and in whose interests. Achieving effective and proportionate governance of health and health-related data will be essential. There remains a tension to be resolved as to whether this is best achieved through the use of central, trusted authorities (e.g. states), as occurs in Taiwan, or whether trust is best achieved through transparency and direct control by citizens of their own data. The striking conflict between citizen (cautious or even negative) attitudes to trust in organisations making use of their explicitly health related data and their attitudes to use of their consumer data, which may be equally pertinent to understanding their healt,h remain to be resolved. This is certain to become more relevant as corporations seek to develop health-related products using data generated through consumer interactions with their products.

A thread running throughout the meeting was the dependence of progress in personalised medicine on the development of so-called 'learning health systems'. These are distinguished from existing health systems in that they embed the cycle connecting data to knowledge to action as the foundation of healthcare delivery, rather than as a parallel activity that is separately governed as part of a linear 'research' ecosystem whose weak connections to frontline healthcare act as a significant barrier to driving change in practice. Learning health systems are also distinguished by being more dynamic and having stronger feedback loops enabling the insights generated from 'big' data analysis to rapidly and efficiently drive changes in medical treatments and the behaviour of citizens - through advice on their health status and the offer of more targeted interventions - and the practice of health professionals.

4.2.5 Blurring boundaries: health and illness, research and clinical care, public and private provision

A common theme underlying many of the discussions within the meeting was the opportunities and challenges presented by a gradual blurring and even dissolution of boundaries that have underpinned the organisational, social and personal conceptions of health and healthcare. This will be necessary in order to enable these learning health systems to evolve. The most notable of these are the boundaries between:

Health and illness – In the context of personalisation and a trend towards a greater emphasis on prevention, issues arise as to the extent to which greater use of sensors (both internal and external) to monitor the health status of individuals is likely to be beneficial. In theory, earlier and potentially more sensitive detection of abnormal behaviour, physiology or biochemistry – using a range of wearable or even implantable devices – could be used positively to enable earlier intervention to prevent the development of ill health or exacerbation of existing health problems. However, as is discussed elsewhere in this report, these developments also have the potential to result in overmedicalisation (a population of worried well), overdiagnosis (a population receiving potentially harmful and unnecessary interventions) and to drive increases rather than decreases in the utilisation of scarce health system resources.

Research and clinical care – Discussions within the meeting placed emphasis on fundamental dependence of the development of more personalised healthcare on dynamic, iterative and learning health systems. An efficient and effective system must be developed for acquiring data (from people and systems), converting it into knowledge and feeding this back into decisions made by citizens and their healthcare providers to enable more personalised healthcare. Currently, health systems make very clear distinctions in this context between the delivery of care, which is quality assured and evidence based, and the delivery of research, which seeks to generate evidence as safely and efficiently as possible but carries greater risks and uncertainties. This approach was compatible with an era of linear, longitudinal, large scale, institutional clinical trials of interventions. However, the expectation is that, for personalisation to develop at pace and scale, more flexible, adaptive and dynamic approaches to testing different approaches to health will be required and the rigid regulatory frameworks that are the manifestation of the separation of clinical and research activity will inhibit these efforts. Notably hybrid models, such as the 100,000 Genomes Project are being considered which aim both to deliver better care to patients and also to develop platforms for iterative patient and system data collection and analysis that can act as a foundation for the future development of more personalised approaches to health.

Looking forward, significant thought will be required as to the steps necessary to ensure the social acceptability of the concept that all patients are, through the act of receiving their care, also participants in knowledge development and quality improvement research that will drive the greater personalisation and effectiveness of care for future patients.

Involving commercial companies in new and positive ways – Linked to the blurring of the boundaries between research and clinical care is the need to consider the changing role of the private sector in a future personalised health ecosystem. One of the key features of a future, more personalised health system is the diversification of organisations involved in supporting individuals to achieve better health. In particular, digital technologies that provide citizens with information relating to health and wellness are increasingly accessible direct to these citizens through apps, wearable devices and monitoring devices that can be installed within the home. These technologies are being developed largely, although not exclusively, by commercial entities who seek to profit not only from the sales of the devices themselves, but increasingly, also from the use of the data they collate.

Positive, collaborative approaches between public and private entities will need to be negotiated that enable citizens to manage their health in a seamless way using a combination of 'products' and interventions, offered both through traditional health systems and through direct to consumer models. The multiplicity of providers presents opportunities to satisfy the desire to respond to varying patient preferences. However, the corresponding need to integrate the vast quantities of data that will be generated across diverse and (not necessarily interoperable) devices and platforms will pose significant challenges.

4.3   The role of governments in balancing (universal?) ethical principles and shifting social values

As well as respecting ethical principles, such as autonomy, the state has an obligation to maintain the health of all its citizens. Governments are at the centre of health promotion and healthcare delivery and are responsible for driving health system efficiency and promoting a regulatory environment that encourages organisations to promote, and individuals to pursue healthy lives. Regulating the control and management of information is therefore a key responsibility of governments and policy makers. However, individuals / citizens also have an important role. Provision of social insurance via a social contract model is relatively uncontroversial unless reciprocity is mandated through enforced deposition of personal data. There was support for individuals / citizens to deposit a 'core' dataset in order to enable the development of a learning healthcare system. It was also noted that a model which emphasises collaboration through shared alliances and incentives could be effective, particularly if commercial companies are involved. This could include companies collecting lifestyle data as an adjunct to their core activities (such as supermarkets) or developers of sensors and associated software (e.g. Fitbit). Enabling innovation and transformation through crowd and open sourcing might be a powerful mechanism for patient empowerment. The aim would be to pursue a bold, evidence-based, networked system funded through a private / public mix.

5.   Delivering change

Throughout the meeting there was a strong emphasis on the need to reconsider the roles different professional groups might be expected to play in the delivery of the transformation of our health systems. These discussions were embedded in the context of an expectation that, whilst policy makers and professionals would continue to shape the health system, the role of the citizen in the transformation of that system would also be profound. This particularly applies to the younger generations who are for the most part digital 'natives', having never experienced a world without internet connectivity and mobile communications. The wider social changes these generations are creating, including increased expectations of access to the benefits of technology and scientific knowledge and of self fulfilment and autonomy in their lives, will need to be harnessed to drive positive changes in social and personal approaches to health.

The question remains, against such a back drop of 'bottom up' change in social attitudes and individual behaviour and expectations, what the role of health and policy professionals and in particular leaders should be in shaping these changes for the benefit of the citizens who are driving them?

5.1   Future role of policy makers in delivering precision health

Delegates debated the role of different policy making groups, including public health professionals, in delivering the radical transformation in health systems necessary to deliver personalised healthcare. The importance of maintaining public health values, particularly the commitment to social justice and equity, and the skills of public health practitioners in gathering and using data to drive quality, efficiency and equity in health systems was recognised. However, there was also recognition of the need to move towards a model where these public health approaches and values are embedded throughout the health system, in particular through changes to clinical practice (by increasing the emphasis on preventing ill health) and through the increased role of citizens in managing their own health and wellbeing. It was agreed that, for as long as the resources available to improve the health of a population are finite, there will be a role for policy makers and public health in shaping how those resources are directed.

This would be particularly important as a way to minimise the health inequalities anticipated to arise from differences in access to consumer technologies and the knowledge that would, in the future provide the cornerstone for much health management activity.

What remains to be determined is the relative significance of public health as a traditional discipline of medicine focused on delivering health to populations through structural interventions, when social change is placing greater power in the hands of individuals to shape their own health, and when, in some countries at least, the size of the state-based organisations through which such structural interventions are typically delivered is shrinking. The linking of personalisation in healthcare to the growth in access to direct to consumer technologies, or at least to a wider range of commercial technology and knowledge companies offering health-related products and information, may serve to weaken the levers through which public health and policy makers can exert force to drive change in population health. The way in which the public health system adapts to this evolving health ecosystem will be a significant determinant of whether personalisation of healthcare can, in the end, lead to greater gains in overall population health.

5.2   Radical change in health systems requires radical leaders

Towards the conclusion of the meeting, increasingly delegates considered the significance of leadership and leaders in delivering the transformation of health systems. The citizen-led, person-centred view of health and healthcare is becoming increasingly prominent in discussions about the future of personalised healthcare. The thesis that the impetus for radical transformation in our health system, and the determination of the direction of that transformation, will come from pressures applied by raised expectations of citizens to have access to the benefits of science and technology and to receive care that is more personal to them. This was thought to pose significant challenges to the system leaders of tomorrow.

There was broad agreement that system leaders would continue to play an important role in shaping the future health ecosystem. The characteristics these leaders would need to possess were considered.

Given that the transformation of the health system envisaged for the future is predicated on harnessing disruptive innovation and the empowerment of citizens, delegates considered whether leaders might themselves be disruptive, emerging from outside the traditional hierarchies of our current systems. It was clear that these leaders would need to be visionary, able to embrace disruptive innovation and to harness the talents, skills and knowledge of an ever widening range of people who contribute to health. In order to be credible, however, these characteristics would also need to be supported by the more 'traditional' management competencies, political awareness and engagement and a sustained commitment to tackling social justice through reducing health inequalities. It was also acknowledged that radical, visionary system leadership would only be able to drive the necessary transformations in healthcare if they created an environment in which the clinical champions essential for the delivery of the benefits of disruptive innovation to patients have permission to take risks and use their judgement to manage the uncertainty inherent in this process. Ultimately, health system leaders will need to create movements for change that are formed from coalitions of citizens and professionals. This will necessarily be a more collaborative process - involving shared decision making and shared risk taking – than those that have traditionally defined the more centralised, authority driven models of change management in health systems.

15

6.   Conclusions

In the concluding session of the meeting, delegates worked together to agree a set of core messages to be delivered through a short communique, to be written by the conveners of the meeting, that could be circulated by participants to relevant stakeholders in their own countries. This communique is included in the report as an appendix. It was agreed that there was an urgent need to engage current health system leaders, professionals and citizens in both grasping the opportunities and tackling the challenges that are described in this report. It was acknowledged that current economic, social and political forces skew most public discourse around health towards tackling short term issues of sustainability and inequality facing all health systems. Nevertheless, the participants remained convinced of the need to invest their efforts in creating and articulating the visions of what future, more personalised healthcare systems could look like as a means to animating the necessary debates at all levels of society about their desirability, feasibility and acceptability, and as a means to motivating the various participants in the health ecosystem to act to bring about the radical transformation that all agreed was needed.

Appendix 1: list of participants

Roza Adany	Professor, Head of Department of Preventative Medicine, Debrecen University, Hungary
Mark Bale	Department of Health, UK
Stefania Boccia	Professor, Catholic University of the Sacred Heart, Italy
Pascal Borry	Associate Professor of Bioethics at Centre for Biomedical Ethics and Law, Department of Public Health and Primary Care, Belgium
Hilary Burton	Director, PHG Foundation
Martina Cornel	Professor of Community Genetics and Public Health Genomics, VU University Medical Centre, Holland
Jan Friedman	Head of The Friedman Lab, University of British Columbia, Canada
Rob Hastings	Senior Manager, Market Development, Illumina, UK
Bartha Knoppers	McGill University, Canada
Katherine Littler	Senior Policy Analyst, Wellcome Trust, UK
Eric Meslin	President and CEO of Council of Canadian Academies, Canada
Walter Ricciardi	Professor of Public Health, Catholic University, Italy
Laura Rodriguez	Director, Division of Policy, Communications and Education, NHGRI, Bethesda, USA
Ron Zimmern	Chairman, PHG Foundation, UK

Appendix 2: post-Ickworth communique

Paths to Precision Health: Act Now

Ron Zimmern, Bartha Knoppers, Eric M. Meslin, Walter Ricciardi

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 biospecimens 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 redesign. 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.

Ron Zimmern, PHG Foundation, Cambridge UK

Bartha Knoppers, McGill University, Montreal, Canada

Eric M. Meslin, Council of Canadian Academies, Ottawa, Canada

Walter Ricciardi, National Institute of Health, Italy