



**OECD-NSF WORKSHOP: BUILDING A SMARTER HEALTH AND WELLNESS FUTURE**

**15-16 FEBRUARY 2011**

**SUMMARY OF KEY MESSAGES**

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## **RATIONALE AND BACKGROUND TO THE WORKSHOP**

1. This document reports on the main points from the discussions that took place at the workshop "Building a Smarter Health and Wellness Future", held in Washington D.C., United States, on 15-16 February 2011.

2. The workshop was co-organised by the US National Science Foundation (NSF) and the Organisation for Economic Co-operation and Development (OECD), and was sponsored by the NSF. The event attracted some 40 speakers and over 150 participants.

3. The workshop's goal was to discuss strategic directions for the future of health and wellness, from both a technological and a policy viewpoint. To this end, a group of experts, including economists, policy makers, social scientists, researchers and representatives of private sector, professional and other associations, were brought together to consider a broad range of issues which are listed under the following guiding questions:

- What are the key drivers of the emergent new technologies, smart models of care, networks and social behaviours? What are the associated challenges?
- What are the extent and form of social, cultural and economic opportunities and impacts?
- How are these developments accommodating innovation at different levels of the healthcare value chain, from new product development to medical practice?
- What can hinder or slow down innovation?
- What are the key issues that deserve further research?
- What roles do economic, social and regulatory factors play in driving and enabling these developments?
- Are there "good practices," particularly in terms of governance that facilitate accelerated technology adoption and social/organisational innovation?
- How effective can government's action be?
- How can countries coordinate research and development efforts?

## THE EXPANDING AND DEEPENING NEEDS OF HEALTH AND SOCIAL SYSTEMS

*Smarter health and wellness systems are needed to support better and more efficient care, encourage greater system-wide accountability and facilitate the promotion of healthy lifestyles and independent living. Introducing “smart” technologies can assist governments tackle the current weaknesses in six key components of health systems: service delivery, finance, governance, quality of care, workforce and information.*

4. In considering the future health and wellness needs, four main drivers stand out which call for smarter solutions. These are listed below.

### **1-Rising health costs and lack of effective and preventive care**

5. An important cause of rising health care costs across all OECD countries is the use of more and intensive treatments resulting from misuse, overuse and/or underuse of care. Poor prevention, unhealthy life styles and lack of effective care has led to higher rates of chronic diseases and related complications. 75 cents of every dollar spent on health care in the United States is spent on patients with chronic diseases. In 2005, this amounted to \$1.5 trillion of the \$2 trillions spent on health care. In public programs, patients with chronic diseases constitute an even higher portion of total spending: about 83 percent of Medicaid and 96 percent of Medicare. More and better information is needed to support wide-ranging improvements not only in the quality and value of care, but across the health care system. This data can do important things to improve quality and effectiveness of care, but can also support other needed changes, such as improvements in medical product safety.

### **2-Demographic changes and increasing proportions of elderly and of very old/frail elderly**

6. In the next four decades the OECD countries face a strong and steady growth in the proportion of population in the ‘older elderly’ group – the proportion over 80 years of age – which is anticipated to increase by 2.5 times between 2008 and 2050. The front runners among the OECD countries are Japan and Korea, in Asia, and Italy, Norway and Sweden in Europe. Norway and Sweden have the highest share of persons aged 80 and over in the OECD.

7. In Japan, the proportion of over 80’s in the population is expected to rise from a current 7% to 17% by 2050, while the EU 27 countries’ percentage is expected to grow from a current 5% to 11.5% – namely, in these countries a greater than doubling in 40 years. While by no means all the elderly have chronic health problems, the rapidly expanding cohorts of elderly and older elderly will include a significant proportion of persons with chronic diseases. Moreover, the last three years of life, regardless of age are on average the most expensive. The number of older people with a long-term care need in Japan is estimated to almost double, from 2.8 million in 2000 to 5.2 million in 2025. In the United States, already some 50% of all adults suffer from a chronic disease and the number of people aged 65 and over with Alzheimer’s disease is expected to increase by more than 50% over a 30-year period, reaching 7.7 million in 2030.

### **3-Increasing demand for home care- in the context of declining health workforce availability**

8. This is a time when expectations are for an increasing amount of home care rather than hospitalization or institutionalization. Home care arrangements account today for more than 30% of the public resources spent on long-term care in many OECD countries.

9. Enabling dependent, older people to stay in their own homes is, however, not only a response to the need to reduce public spending. Today's pensioners have higher incomes than previous groups and can afford to pay more for their own care, and housing standards have risen. This will produce more demand for home support workers, which is already a stretched workforce. The traditional solution of wealthy countries, that of importing workers from lower wage economies, is not sustainable as a solution either ethically or practically, as each country's health and care needs will expand. Recent studies from the OECD point to a possible long term care workforce crisis.

### **4-Demand for more responsive, patient-centric services**

10. Not only will the number of people needing support increase both in absolute numbers and proportionally, but a growing proportion of them will be increasingly informed and concomitantly demanding for more responsive services. Use of information technologies means that the amount of health-related information in the public domain is increasingly exponentially, but also that this is increasingly accessible to the non-specialist citizen. The balance of power is rapidly shifting from the paternalistic health professional treating the compliant patient to informed citizens who are active partners in their care, coupled with an increased choice and preference for home and independent living.

## THE CONNECTED PATIENT

*Better health outcomes require greater patient empowerment. Social networks are providing an environment conducive to greater ‘co-ownership and co-production’ of health and wellness. They represent a new participatory care paradigm and are transforming the way patients connect and communicate, share personal health information, discover and access new care options. The effectiveness and utility of these social networks for accelerating diffusion of information on healthy life styles, fostering behavioral modification and health innovations, including clinical research, needs exploring.*

11. Advocates of patient-centred health have long argued for the citizen taking responsibility for their own health. The argument today, widely applies to the management of chronic diseases such as diabetes and obesity and health systems increasingly see their roles as agents of support. To the extent that individuals are the best judges of their own welfare, the chances of success of any care or prevention programme will depend on patient engagement and meaningful co-ownership and co-production of healthy behaviours.

12. The development of comprehensive, smart alternatives will, therefore, need to take account of how individual choice and values are evolving. Many patients today explore local and global information sources, leading to the concept of an ‘*expert connected patient*’. Disease interest groups, social network sites, and self-help information-sharing Internet sites facilitate and fuel this trend. Awareness and information on healthy choices today increasingly pass through these networks. Social networks, in particular, may trigger and influence innovative care behaviours at the individual, organizational and community levels. Willingness to share health data through these communities is also opening entire new public health research opportunities to understand disease progression, patterns of illness, and responses to treatments, including patient experiences.

13. Key issues in the context of these developments are:

***1-Personal health records, social networks and virtual communities are providing patients with unparalleled access to information and greater ownership on choices over prevention, treatments and providers***

14. In many cases, patients with rare or stigmatized disease may not have a rich support group that is geographically accessible. By providing tools for patients to seek out and communicate with others undergoing similar experiences, patients can access information to evaluate what works and what doesn’t work in closely matched cohorts and bring that information to their care providers. The health professional must, therefore, increasingly justify and negotiate their planned course of action – a trend which

philosophically cannot be faulted, as it is the patient's health not the professional's which is the focus of attention, but this trend is nevertheless uncomfortable and challenging to many health professionals. Within the past few years, in countries across the globe the power of social networks has shown that health providers and regulators need to respect and work in tandem with these expressions of unconstrained citizen communication.

### ***2-Social networks' 'openness philosophy' poses challenges to pre-established privacy norms***

15. Social networks involve users communicating with users as equals seeking the same balance between privacy rights and informational benefits. User behaviour in health social networks suggests different attitudes toward privacy than we might expect in face-to-face interactions. In the course of using a social network, members may share information that could be used to reasonably identify them (personal information), including name, photograph, and email address. Sensitive information that members provide about themselves and is widely shared with the social network community may include personal details like prescriptions, genetic disease, sexual dysfunctions, and surgical or other treatment complications that would be considered imprudent to share in public and which would certainly violate most privacy legislations if released by health care providers. It is possible, of course, that many users do not grasp the longer-term privacy implications of their actions.

### ***3-Online communities not only provide a place for members to support each other, but also contain knowledge that can be mined for public health research, monitoring, and other health-related activities***

16. Social networks are providing patients with life-changing illnesses platforms for finding other patients matched on demographic and clinical characteristics, and learn from their experiences while at the same time researchers can study aggregated data reports. There is growing recognition that online communities not only provide a place for members to support each other, but also contain knowledge that can be mined for public health research, monitoring, and other health-related activities. While this trend can be generally judged positively, in the absence of agreed quality assurance, it may bring related new risks ranging from patient selection bias to possible malicious exploitation of health data.

### ***4-Social networks are effectively mobilising online communities to "coach" and foster healthy life styles***

17. Social networks seem particularly well suited to empower patients through coaching and for supporting change of behaviour as social interactions can generate a high 'persuasive potential'. They can intervene at the right time, in the right context and in a convenient way. This is important because one of the prerequisites for a patient to become an active participant in his or her care is self-confidence and motivation. Unsurprisingly, new prevention programmes are effectively mobilising these online communities on health and wellness issues to foster healthy life styles. As these online communities are growing in numbers and scope, there is a need, however, for further studies on their quality, safety and effectiveness.

### ***5-Toward a new Economy of Donation***

18. Increased health information sharing creates a useful resource on disease treatments and patient self-reported outcomes, an advantage that *PatientsLikeMe* explicitly embraces in its "Openness Philosophy". The observation that patients are "ready and willing to share with each other so that other

people can benefit from their experiences suggests the need to look beyond a purely information-seeking behaviour. Patients may surrender privacy not simply to gain emotional or informational support for themselves but to provide such support to other members of their online community. Indeed, some users of health social networks report finding information that they otherwise may not find among their regular health providers.



## NEW SMART MODELS OF CARE: FROM PERSONALISATION TO UBIQUITOUS CARE

*The opportunities presented by mobile technological platforms, greater information storage capabilities such as through cloud computing, transmission and processing technologies, new sensing technologies, and computing power are such that it is possible today to deliver care in wholly new ways. The health and care sectors have, however, been slow to make radical re-engineering moves. The depth of investment into current structures, professional innate conservatism, regulatory uncertainty, and above all the asymmetry of information and problems related to patient empowerment and accountability, until recently, have held back change.*

19. A typology of a few of the emerging new models of care described at the workshop is presented below.

### **1-Personalized Medicine**

20. The power of health information processing is such that it is possible today to personalise therapy in wholly new ways. Culture, living style, belief systems, and expressed choice are one dimension. Secondly, the ability to search and process electronically recorded medical histories for the individual enables the rapid identification of not just personal biological responses such as allergies, but a much richer pattern of personal information such as pharmacological responses, results of diagnostic tests, and outcomes of particular therapies. Thirdly, new genomic knowledge can help identify population group variations which influence care response, but also personal genetic profiles which can inform not just individual therapy but also selective targeted prevention.

21. Whole genome sequencing, expression profiles and other high-throughput technologies also promise to create a post-genome paradigm shift in health, disease prevention, and personalized medicine. However, this paradigm shift will not take place until the technologies and processes are re-engineered from use in the research setting into use at point of care. Effective translation will also require the development of bioinformatics tools, methods and analysis to process and integrate personal genomic data into electronic health records (EHRs), addressing reimbursement issues, and creating a robust clinical business model for post-genome pathology practice. These and parallel efforts though difficult, disruptive and time consuming, will catalyze the adoption and widespread implementation of the post-genome competency required to fully capture the value of whole genome information and thereby enabling the coming era of personalized medicine.

### **2-Participatory Mobile Health**

22. M-Health is by far the fastest growing segment of IT-based health care delivery systems (e-Health). A wide range of devices are utilized for M-Health today, including *inter alia* mobile phones (in

particular smart-phones), tablets, global positioning system (GPS) devices, mobile tele-care devices, mobile patient monitoring devices.

23. Participatory M-Health can incorporate a variety of these techniques, including automated activity traces, reminders and prompted inputs. Intended to be used episodically, rather than continuously, M-Health solutions can assist patients with adherence to their treatment regimen and provide useful information for clinicians. Employed by individuals, they can glean insights into what might be contributing to the recurrence of a chronic problem, or help them track and sustain a plan to become healthier through better diet, exercise, sleep, and stress management.

24. The software and methodology for Participatory M-Health are adaptable to a wide variety of health interventions. From a research perspective, four issues are key to the successful implementation of M-Health: i) establishing and sustaining engagement among participants; ii) widely accepted privacy and security standards for personal data collection, analysis and use; iii) integration and interoperability-the new range of mobile devices have to function seamlessly and adapt to multiple user needs in the health sector ; iv) financing and the new business models: there is a need to adapt regulatory structures and align incentives at different levels of the health delivery system to encourage investment in, and use of, M-Health.

### **3-Ubiquitous and Pervasive Patient Care**

25. The ubiquitous care model is based on the utilization of smart sensing and biometric devices for real-time monitoring, analysis and transmission of health data. The information can then be accessed by healthcare providers for informed diagnosis, clinical decisions on treatments, and evaluation of outcomes. It can also be viewed and acted upon by patients for both education and prevention.

26. The technology to support ubiquitous sensing already exists and an increasing amount of physiological monitoring data streams are today displayed on medical devices around the world every day. The key challenge is to combine these technologies with network infrastructure to create an integrated architecture and extend care outside the hospital to the home and mobile patients. For example, in the case of managing patients with acute diabetes, the blood glucose level can be monitored continuously in vivo, which controls the insulin delivery from an implanted reservoir. In cardiology, the value of implantable sensors for continuous monitoring of the most important physiological parameters for identifying the precursors of major adverse cardiac events -- including sudden death -- has increasingly been recognized. The data streams provide enormous potential for improved diagnostics, prevention, support of evidence-based practices and remote health care. These data can yield answers to clinical questions or raise new questions that influence care responses.

27. By and large however, this process of ubiquitous real-time monitoring of patients is information intensive; the information generated is often not only fragmented but also spans multiple processes, parameters, and decision criteria. This can lead to an information overload of healthcare professionals and significant network traffic. In addition, the vast majority of the data streams are often lost once they have passed off the monitor screens. Effective conversion of the information into clinically actionable knowledge will, hence, depend on the development of robust algorithms and computational models that can fuse and derive meaning from the diverse sets of information. Key factors influencing scalability,

therefore, include: i) seamless integration and interoperability of the technology ; ii) reliability of message capture, translation and delivery to healthcare professionals and the amount of information transmitted per patient; i) frequency of monitoring and transmission and context awareness.

#### **4-Person-Centric Care**

28. All the aforementioned models of care hold the potential for greater patient-centric care. Bringing multiple professionals and provider organisations into a ‘virtual team’ round the patient means the patient enjoys an integrated service, and does not have to arbitrate between service components; it should also be cheaper and more efficient. However, it brings new issues of team working, negotiation and concordance, not least when one agent’s action affects the demand upon another’s resources. New liability issues arise. Apart from the patient, who takes overall responsibility, and to what degree can this impose upon other autonomous organisations and professions?

## A RAPID LEARNING HEALTH SYSTEM

*The emerging new smart care models will need to be extended and integrated to increase the value to society and patients. The underlying infrastructures need to be interoperable to provide the technical support for an expanded set of information exchange scenarios required for a Rapid Learning Health System.*

29. Deep mining of data from electronic health records (EHRs) and other distributed ICT systems creates an enormous potential for monitoring the performance of health systems, to assess and improve the quality of health care, better understand the determinants of health and outcomes, and to conduct clinical and translational research at speeds approaching real time. In such a context, health system derived data can be processed against societal and other data to uncover patterns of behaviour and causality as well as trends in the incidence and prevalence of health problems, radically changing the nature of public health, health promotion and clinical research.

30. When this process can happen routinely, with mechanisms in place to establish and maintain public trust that the process is secure and private, a country will have substantially progressed toward establishing a so-called *Rapid Learning Health System*. Examples of what can be achieved at relatively small scale include Kaiser-Permanente and academic medical centers such as the Mayo Clinic or Duke University.

31. Taking the learning system from an idea to a working reality will, however, require mutually reinforcing and interoperable technologies, standards, and policies created in specific anticipation of secondary use of data stored in EHRs and other devices. The degree to which EHR systems can facilitate health data collection is constrained, however, by limitations such as the prevalence of data recorded as unstructured narrative or text, lack of standardization for data content, and data privacy and access issues due to silos created by legacy systems and organizational boundaries.

32. In many countries, population health monitoring and health statistics are still explicitly secondary to the primary uses of EHRs. Consequently, the conceptualizing and implementation of EHR systems do not typically incorporate elements for their use in population health and health statistics or clinical research.

33. Nonetheless, it has been stressed that there is great potential for shared EHRs to lead to real-time decision support systems and feedback loop systems for clinicians, public health practitioners and policy makers. What is now regarded as clinical data could be transformed into statistical data at both individual and population levels. Although the data may be collected for clinical patient management purposes, they also will have a high yield for health system monitoring and research.

## TOWARDS A NEW HEALTH DATA FUTURE

*Advances in cyber infrastructure have created a virtual deluge of new types of data ranging from new data on human interactions through digital imaging, sensors, and analytical instrumentation to new ways of collecting biological and geospatial information and to combining data from different sources, such as clinical and administrative records. Effective use of new, smart, technologies requires ‘making sense’ of these data to support the new patterns of collaborative and integrated person-centric caring; enable social learning; adaptive organisational change; healthy lifestyles and behavioural modification; and clinical research.*

34. It is predicted that more medical information and health data will be generated in the next few years than ever before – all of which must be mined, stored securely and accurately, and converted to meaningful information at the point of care. For example, data will be automatically populating electronic records to be used for afferent and efferent activities:

- Preventive care, e.g. early detection;
- Field data in support of emergency and urgent care;
- Coaching, rehabilitation and maintenance;
- Context-sensitive intervention, e.g., reminders;
- Epidemiological assessments;
- Post-market surveillance and analysis;

35. This will require real-time continuous archiving of multi-modal datasets and multi-domain collaborative annotations, and post therapeutic visualization of the archived data. The volume of this structured and unstructured health data is set to increase dramatically with advances in M-Health, sensor and imaging technologies to support diagnosis and treatment. There are, however, challenges in getting these data out of the different clinical information systems and monitoring devices.

36. Today, where electronic data does exist, it is tied to specific applications which are often not interoperable and may be hard, if not impossible, to merge and meaningfully process these data. In addition, incentives to sharing/exposing data are limited. There are also specific challenges in getting non-health care data into integrated records. Heterogeneous data processing needs adaptive filtering of signals set to meaningful threshold and/or pattern changes. There is also a need for tools to enable data cohesion (for example, avatars for locating, collecting data that is stored in distributed systems).

37. There is value in retaining both unstructured/fuzzy (such as patient or doctor narratives and surveillance reports) and structured health data. As EHRs and other health informatics devices become increasingly widespread, harnessing unstructured data may yield valuable information. For example, information could be gathered to find predictors for diseases or adverse effects of treatment that would

otherwise have gone unnoticed by most traditional research studies. Though challenging, capturing and delving into this data is worth the effort and research on new data-mining, analytical and computational tools are needed to be able to recognise and process semantically equivalent information from heterogeneous sources.

38. Organizations will need to manage and retain large volumes of structured data long term. Achieving this in a cost-efficient, scalable manner to meet future growth represents what some call ‘the big-data retention challenge’. Finally, as well as being stored effectively, information must be made readily accessible to support health care professionals at the point of care.

## **ACTIONS TO BUILD A SMARTER HEALTH AND WELLNESS FUTURE**

39. The workshop was an opportunity to discuss and determine areas where the OECD can provide further policy insight and expertise. The sections below summarise the main messages and recommendations for international actions and research.

### **1-Address the Data Challenges -- for Smart Health Systems and Society**

40. Automated information systems, the information gathering processes and the data sets they compile have hitherto largely mimicked the manual paper-based processes they replaced. However, those processes were constrained by the limitations of the paper records and mechanical means of data transmission. In the era of advanced informatics systems there is a need to look beyond current constrained thinking, and be far more radically innovative (within ethical bounds) to gain maximum yield from the distributed information sources and large electronic databases now emerging.

41. This innovative use of data should be at several levels and in multiple dimensions – for example, within contexts such as primary and domiciliary care; across these traditional care divides so as to give patient-based or population based views; crossing health business areas, such as linking prescribing patterns to demographic data; and linking types of care particularly ensuring health care and social care are linked. But there is important scope also to look at data outside the health domain and link population data from different sources to better understand environmental determinants of nutritional illness, stress, mental health.

42. Also, a new paradigm of data becomes available with remote monitoring. This may be vital sign and other clinical monitoring, for instance monitoring complications in pregnancy or specific clinical conditions attributable to a chronic illness, or it may be daily living monitoring to identify quickly when a frail person has an adverse incident and needs help. These monitoring opportunities should be developed, but sensitively to ensure privacy and acceptability. It will be just as important to develop appropriate and integrated care responses. Large streams of monitoring data are of no intrinsic value but are of high cost, and may create a false sense of security. Of vital importance are, therefore, the development of new powerful approaches to draw meaning from the data and of responsive services to act on that data.

43. Meanwhile, in aggregate, the data should give new research opportunities for understanding and forecasting changes in essential clinical processes and interventions, and of patterns of daily living amongst the elderly or those with specific diseases.

44. The complexity of health data use is clearly growing exponentially. Conventional technology today cannot effectively manage or even capture the many health data streams, and ensure that they will be turned into useful and actionable health information. The growth of '*big data*' is literally forcing health organizations to revisit and rethink their infrastructure and capacity plans or else 'drown under the weight of cost and compliance'.

***The key issues for further policy action and research are:***

- The benefits and risks of ‘big data’ collection need to be carefully considered prior to collection as it is important to ensure that data can be turned into useful and actionable health information
- Interoperability between devices, applications, services, etc., is important; and the use of common commercially available standards is key.
- Need for better linkages of health and wellness data with social, environmental, and sensor data (with interoperability and support integration as prime goals).
- “Big data” retention, management and data services challenges, including more effective approaches for extraction of knowledge and meaning from heterogeneous sources to inform health and care systems.
- Integrated sensing, clinical and service design research on how to turn sensor data into actionable data, e.g. the transfer of the “intense care unit” (ICU) monitoring paradigm into home and other monitoring, on how to combine multiple signals to identify key events, minimize false alarms, and ensure appropriate response.
- The development of efficient databases and user interfaces to allow access to appropriate data at the point of care is needed. Analysis and visualization tools must, therefore, be designed along with the applications, and users should be able to view partial results – presented in a useful and engaging way – during the collection process.

**2-Foster Meaningful Innovation**

45. While smart technologies are being shaped in this nascent period, an open, shared architecture is essential. Just as the decision to build the Internet on a common IP protocol with open interfaces on all sides was critical to its success, and just as more recently the Android market and Firefox browser have made it easy for third-party developers to innovate and proliferate, an open architecture can pave the way for rapid exploration and innovation in this sector, as well as iterative improvement.

46. Innovation, however, needs to be far more than technological innovation. Health care responses, and means of delivering smart services, need radical organisational and social innovation given the multiplicity of actors with different cultures and roles, including both public and private sector stakeholder point of view. Replicating a historic “silo”-based approach will limit the potential of the new range of smart care solutions. This also means that devices will have to function seamlessly and adapt to multiple user needs in the health sector and partner sectors.

47. Innovation must also consider how health and wellness support focus round the patient/citizen, with co-ownership and co-production by the subject and their nominated trusted carers – recognising that each individual will have vastly different informal support in both quantity and competence available. Such innovation will require changes to concepts, professional roles, inter-professional collaboration, funding, legislation and regulation, and quality monitoring. As well as building forward views as to how



technology may enable change to current practice, foresight exercises and simulations should seek to build back from how citizens might optimally be supported in say 2030 and 2050 and identify the transformation paths necessary.

*Examples of the key recommendations raised at the workshop are listed below:*

- An open innovation ecosystem is needed to accelerate innovation for greater system-wide integration and scaling.
- Frameworks are needed to identify and support the move from silos of technology to an integrated ecosystem of smart solutions – including multidisciplinary approaches (integrating research on technologies, health and care systems, and societal systems). Research funding systems need to be able to support such cross-disciplinary research, including scaled evaluation, while professional, legal, and other constraints need to be adjusted to enable this work.
- Exploration and exploitation of the potential of open platforms, open innovation, products and processes to help foster and accelerate pre-commercial innovation
- Identification of means to support iterative research and effective international coordination and collaboration; use existing and new techniques to lay groundwork for more fundamental research.
- Examination of the range of incentives or mechanisms that have been applied to influence innovation – in research, application development and implementation, and practitioner and citizen use – identifying drivers to innovation, and also the barriers (many of which may be based on sound but potentially outmoded principles and concerns).
- Develop and share understanding of the roles of system, social and community contextualized innovation.

### **3-Understand and Address the Potential New Risks**

48. With any new technology or other innovation come new risks, and new unanticipated outcomes. While it is right to pursue and promote new opportunities rigorously in the interests of citizens and society, equal thoroughness must be given to the development of quality assurance, monitoring in use, identification of potential adverse outcomes or intentional abuses, constructive reporting and analysis of incidents and events, and creation of appropriate controls, mechanisms, and regulation.

49. Health and wellness research faces strong pressures to develop and deploy rapidly. In the case of pharmaceutical innovation, strong mechanisms have been built up to promote sound practices for research and development including testing effects and linking the scientific outcomes to guidance and controls. Health informatics and health systems design and redesign have not been so rigorously served, even though there are documented examples of adverse outcomes and there are potential risks of unauthorized data access and disclosure and of loss of data integrity. Increased communication capabilities may open systems to exploitation by hackers who exploit security gaps for purposes of fraud. Increased data availability may enable privacy abuses where patient data is used inappropriately. System failures may

affect data integrity in a way that leads to safety violations. Finally, increasing data liquidity creates new threats from compromise especially from outsourced repositories (cloud services).

50. Particularly when contributing data about their health and living patterns, many participants are understandably concerned about privacy issues. The challenge for system designers is to balance the inherent benefits of the new smart technologies against the risk of revealing too much personal information to third parties – in essence to build *Privacy-Aware Health Information Systems* – i.e., to build systems with user-controlled privacy and verifiable assurances, that are flexible with regard to data access conditions and patients’ preferences over time.

51. Measures are needed to mitigate these threats and ensure that residual risks are acceptable. This situation must be redressed as part of the ethical development of smarter health and wellness systems in the new information-based society.

***Priorities mentioned at the workshop include the following actions:***

- As teamwork and integrated care develop, data sharing becomes wider, requiring new paradigms and regulations on who should have access to data, how much to share, and with whom. Widely accepted privacy and security standards for health data collection, analysis and use are needed.
- Identification of critical lessons and guiding principles to achieve privacy by design in health systems, including remote and mobile systems – not least the role of the patient in expressing control to determine differential access to personal data.
- Explore broader policy implications of mining, storage and use of information collected by social networks about individual health profiles; including the benefits and risks of open sharing of personal details on social sites (including health-based ones).
- Support further research on the impacts of “disintermediation” (“taking the doctor out of the picture”) and behavioural modification platforms (e.g., to increase patient adherence of prescribed drug therapy and wellness initiatives) – including the new and evolving balance between personal and social responsibility on health.
- Explore the risks and opportunities of ‘fuzzy’ data.
- Identification of the risks to quality (and to sound ethical practice) of remote monitoring, distributed care delivery, virtual teams, and informal care provider co-production, and creation and validation in practice of new paradigms of quality assurance and quality control, including dimensions of a ‘learning service’. Such paradigms must be able to cross traditional organizational and professional boundaries as well as work within them, and citizen viewpoint and choice must be accommodated appropriately.
- Undertake sociological and behavioral research, based on an open and listening approach with citizens and with practitioners, to ensure that the caring is not taken out of health and social care with the increasing use of technology and standard responses, while ensuring that support is efficient, effective, and accessible.

#### **4-Support Concerted Effort to un-Silo Communities for a Virtual Care Future**

52. Efforts must be integrated, coordinated, and avoid overlap or duplication. However, the dual steps of ‘demolishing’ professional or sector-specific silos, and of moving from fixed and institution-based provision of care towards ubiquitous care provision based on remote monitoring, are challenging and also require disruptive innovation of many existing processes. This radical change is vital, but must be managed sensitively and constructively. Establishing and sustaining engagement among participants is critical to the success of these initiatives.

53. Existing processes have developed for good initial reasons; in their existence, they also give frameworks for comfort and stability, certainty and accountability, development and satisfaction. In the new order, new processes will need to be developed which fulfil the same important needs, but also support the new integrated working and are not restraints to innovation.

54. At the same time, communities are not homogenous and do not consist of identical citizens. Individuals and families vary in many ways, and of particular relevance for the health and wellness agenda are education, income and financial resources, lifestyle and family size and structure. Influential for many are belief systems, cultural and ethnic backgrounds, and employment or vocational history. Thus, a challenge to looking to the structure and modalities of future smart care support is to ensure that it is equally available and accessible to all, within the context of the national patterns of care provision.

***Particular amongst these challenges are:***

- Research on the risks and opportunities of the paradigm of a mixed economy of care, and with this how to measure ‘quality’, and how to link to individual and team responsibility.
- Encouragement of research on incentives for new patterns of virtual care involving professional services, family and informal care providers -- including on the new business models, the implications of changing roles, potential liability issues, and roles, needs and rights of informal care providers.
- Addressing issues of equity of access, acceptability and appropriateness, and new risks of a new e-health divide and service disempowerment with new smart e-enabled paradigms and potentially intrusive and impersonal technologies.

## NEXT STEPS

55. The Workshop presented a number of recommendations for international action and areas where the OECD may decide to do follow-on work.

56. A few of the issues raised by experts at the workshop are already taken forward by the OECD project on *ICTs for a silver economy*, which aims to further explore how smart technologies can be leveraged to innovate services and address the challenges of ageing societies.

57. Additionally, one of the strongest conclusions from the workshop is that portable technologies and M-Health are rapidly evolving fields and could provide a good starting point to explore how to best move forward. M-health is by far the fastest growing segment of IT-based health care delivery systems. These technologies can increase patient access to health services and information, patient empowerment and self care and improve the way health professionals deliver health services -- particularly for chronic disease prevention and management. The implementation of M-Health continues, however, to face significant challenges. The OECD-NSF workshop outcomes point to the need, therefore, of a multi-stakeholder policy framework to create the conditions for sustainable and scalable m-Health, and to accelerate innovation in this area.

58. The OECD Secretariat has identified the following six areas where further analytical and policy work at international level could be useful, using M-Health as case example:

**Network infrastructure:** M-Health applications require sufficient capacity, very low latency and high quality of service guarantees in order to work safely and efficiently.

**Data challenges and the need for trusted services:** systems need to be designed to deal with personal health (and other relevant) data. Widely accepted privacy and security standards for personal data collection, analysis and use are needed.

**Integration and interoperability:** a “silo-ed” approach will limit the potential of M-Health: the new range of mobile devices has to function seamlessly and adapt to multiple user needs in the health sector. How can governments accelerate innovation and greater system-wide integration and scaling?

**Financing and the new business models:** there is a need to understand the regulatory structures which provide incentives at different levels of the health delivery system to encourage investment in, and use of, m-Health.

**Evidence-based implementation:** metrics will have to be developed to monitor and assess M-Health utilisation, identify best practices, and generate economic models for planning and analysis.

**Capacity-building and training:** there is a huge demand for training of health providers in the use of M-Health and for innovative solutions that support community health workers, and improve patient understanding and use of these new tools. Case studies could be useful to identify best practices. (the OECD is, for example, already looking at strengthening analytical case study work on ICTs for a silver economy).