

# "It's All About Me": The Personalization of Health Systems

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# Introduction

Health systems have experienced unprecedented change in the last several decades, resulting in new ways for consumers to seek and engage health services and revolutionary technologies that have completely transformed how health challenges are managed. Consumers can connect virtually to global experts to access information about health. Discoveries in genetics are providing a mechanism for consumers to evaluate their risk for disease. Pacemakers are able to wirelessly transmit heart rhythms, enabling individuals with cardiac arrhythmia to connect to a cardiologist. Yet, these impressive advances may not have realized their potential in the populations they serve. Why? Health systems around the world are challenged by increasing demands for healthcare services in the face of diminishing economic resources. Every developed country in the world expends substantial economic resources on healthcare which has driven health system priorities to focus on cost containment and sustainability. Yet, as health system costs continue to increase over time, the value health systems are able to achieve for the population they serve remains unclear. Why is it that despite decades of advances in science, health systems struggle to deliver value to populations they serve?

Health systems have long been focused on delivering services to treat, manage, or cure disease, illness, or injury; they are not so much "healthcare" systems, but rather, "disease management" systems. Health services focus primarily on assessing and diagnosing patients, prescribing care and treatments based on standardized protocols or best evidence available for a particular disease or condition. Traditionally, health teams have been the key decision makers in most health systems and consumers are the "patient" who is viewed largely as the recipient of care. Although many health systems aspire to deliver "patient-centered care", health professionals primarily focus on making decisions for, and occasionally, with the patient.

In recent decades, the desire to improve the quality of care while reducing health costs has led to a focus on standardizing services to ensure every patient has access to high quality health services. To achieve this, health teams have embraced clinical practice guidelines and evidence-based care planning to direct their day to day practice. Although this has achieved great value for health systems in terms of quality outcomes, the scope of most health systems has remained narrowly focused on the safe and effective management of disease, illness and injury and a top-down style of decision-making whereby health professionals are deemed the experts, and the focus on managing disease has remained virtually unchanged even in light of the new resources available. In addition, there has been little attention placed on whether health systems are delivering value to the populations they are mandated to serve, both in terms of the nature of what they are delivering and also in terms of the fact that people want to be treated as people and not the substrate for diseases. The things that matter to them are not necessarily what a "one size fits all", disease focused evidence based system can deliver.

This traditional structure worked very well over the last 50 years for two primary reasons: health providers were the primary (and often sole) source of health information; and, the pace of scientific discovery was steady but not revolutionary. First, health provider teams - led by physicians - had more or less exclusive access to all health information, serving as brokers of what information was shared with their patients and when, based on their assessment of what they felt was needed. Exclusive access to, and control of, a patient's health information gave physicians high positions of power over the patients they cared for. However, advancements in communications technologies have shifted this power dynamic. Entire populations are now connected through the World Wide Web, which is accessible through an expanding set of technologies including mobile phones, computers, and tablets.

The growing availability and affordability of internet access enables information to flow freely across global borders, connecting individuals, health experts, and organizations. Access to information and opportunities to communicate in new and different ways have strengthened health literacy, defined as the working knowledge and language of healthcare. Global populations, particularly those in developed nations are emerging as informed consumers of healthcare, rather than passive recipients who simply "follow doctor's orders". Increasingly, people decide for themselves whether they will follow the prescribed care they have been given, and readily seek advice and information on health issues from a variety of sources beyond their primary health provider. We can gauge how well we are doing in our delivery of healthcare if we consider how many people stick to their treatment plan. As many as half the people who are initiated on a medication are not still taking it within a year. This is a real indictment of the system. We have lost the connection with the people we treat because the plans we make are not perceived by them to be for them.

Second, there have been a number of recent advances in science which have generated extraordinary new ways to treat disease, manage risk of illness, and more effectively achieve outcomes for patients. These include genetic therapies which treat individuals based on their unique genetic make-up. For most health systems, supporting the cost and implementation of genetic therapies and treatments requires a completely different structure and funding model, in addition to substantial resources to support new therapies. As an example, traditionally, clinical practice guidelines have been used to achieve highly standardized care for people with specific diseases such as cancer. Genomic therapies demonstrate the differences with each individual, providing the ability to generate a personalized plan that maps out the timing and nature of transactions of care for every individual experiencing a particular disease or illness. While these types of technologies and therapies hold great promise for disease management, this type of personalization is expensive and does not allow for economies of scale. Funding models that are able to support the integration of new "omics" therapies into health systems remain a significant challenge globally, particularly true in countries that follow a more socialized system of medicine where access to the therapies and technologies would need to be made accessible to all.

These two drivers of change, unprecedented access to health information and revolutionary medical discoveries, are working together to generate a grassroots demand for personalized healthcare. However, given the current system focus on standardized disease management, most health systems are not designed to respond to this demand for personalization. Essentially, health systems are at an important crossroads. Health systems are under substantial pressure to deliver value to the populations they serve within limited fiscal resources, while at the same time, the role of the consumer is evolving as they begin taking steps to engage and manage their health and wellness in a manner that is personalized to meet their unique needs. To date, the personalization of healthcare has only been examined relative to the delivery of genetic based therapies and treatments for disease. There has been little consideration for how the emerging information and communications technologies, and advancements in genetic based therapies can be organized to achieve the personalization at the level of health systems. However, information technologies are widely viewed by global health system leaders as a key enabler of the diffusion of health system innovation that will fundamentally drive transformational change globally. What is critically important about information technologies is that they enable the engagement of entire populations of consumers, who now use online tools to access the health information needed to manage their health and wellness, and connect to health system experts, clinicians, and services globally. Essentially, the boom of information and communication technologies is a major influence in driving the emerging personalization of healthcare globally.

The purpose of this paper is to examine the personalization of health systems in a way that goes beyond the clinical consideration of personalization at the cellular/genetic level, and begin to consider personalization that is focused around individual and population-level health goals enabled through greater access to information technologies. To do so, we consider the following questions:

1. What matters to individuals in regard to health personalization?
2. What are the emerging trends in technology and consumer behaviour that are contributing to and influencing the personalization of health systems?
3. What are the key personalization strategies that have been successfully used by industries and organizations outside of healthcare?
4. What could a personalized health system look like?
5. What are the necessary steps health systems must undertake to achieve personalization?

We begin by considering the philosophical motivation for personalization as a necessary and important building block for the personalization of health systems. We then examine existing trends in personalization among consumers as well as lessons learned from other industry sectors and organizations that have achieved personalized models of service delivery. Using this data, we suggest a model for a personalized health system, illustrating the transition from the current system to a potential personalized end state. Finally, we propose 10 steps individuals, health providers, health system, and policy makers need to undertake in order to create and accelerate the personalization of health systems.

We recognize that some of our ideas are provocative and challenge conventional patient-provider relationships and traditional system design. However, we strongly believe that in order to create health systems that are truly focused on achieving the goals as articulated by patients, everyone involved in health systems must change their perspective in every facet of healthcare to allow for the creation of innovative, personalized solutions and health experiences where it is not all about the system, but rather "all about me".

# Section 1: Personalization: What Matters to People

Personalization in healthcare is not a new concept. Over 2000 years ago, the Greek physician Hippocrates emphasized the importance of individualizing medical care proclaiming, "it is more important to know what sort of person has a disease than to know what sort of disease a person has"<sup>1</sup>. Personalization in this traditional sense means that individuals are able to seek healthcare services and treatment tailored to meet the unique challenges of a particular disease or condition they are experiencing. Advances in both "omics" sciences and information and communication technologies, offer health systems a new way forward to "personalize", by engaging these technologies to focus on achieving value in terms of what matters to people - quality of life and wellness. As a result, a very new perspective on personalization is now emerging which is very distinct from Hippocrates' vision. The purpose of this section is to examine the potential for personalization of health systems, far beyond personalization at the level of individual patients, to consider how health systems can leverage these emerging trends to achieve sustainable personalized health systems that deliver value to the populations they serve.

## What is Personalization?

The concept of *salutogenesis*<sup>2</sup> provides a strong theoretical basis for defining personalization. Salutogenesis, first described by Antonovsky in the 1980s,<sup>3</sup> defines health relative to what matters to people, where the ultimate goal of healthcare is to enable or facilitate health which is viewed as a key determinant of quality of life. Lindstrom and Eriksson (2011) use the analogy of the "river of life" as a potential vision for personalized health systems. Downstream, healthcare systems offer disease management, which can be likened to trying to save people from drowning in the river. Upstream, healthcare is more closely aligned with people's values of health and wellness to achieve quality of life, and is designed to prevent or mitigate risk of disease which compromises health and wellness. In this vision, healthcare systems offer a balanced portfolio of services to populations, both supporting people so that they can experience a good life where they are well and healthy, and providing supports when disease or illness occurs so that individuals can be rehabilitated and returned, where possible, to good health. In this paper, we primarily consider personalization through a population-based lens where health systems strive to achieve value for the populations they serve, namely health, wellness and quality of life, which varies across population health sub-groups based on factors such as age, communication or literacy, risk, and so on. In order for health systems to contemplate personalization, one must first examine the key conditions for personalization based on the philosophical dimensions of healthcare that matter to people and reflect value.

## Conditions for Health-based Personalization Based on Value

If health systems are to deliver value to the populations they serve, it would require that value be defined in terms of quality of life, health and wellness, as an alternative to the more narrow focus on disease and illness. Value-based outcomes, beyond those that are purely economic in their construction, are not currently defined or measured by health systems. Indeed, one of the greatest challenges health systems face is delivering value to the populations they serve in a way which is meaningful to health consumers, and sustainable from a cost perspective. How can health systems re-orient their mandate towards value? In order to transform current disease focused healthcare system models to focus on value, quality of life and wellness of the population need to be central tenants of all

mission, vision, and values through health systems. A first step requires a better understanding and consideration of what people value and need from their healthcare systems, and how people want to engage in healthcare services in order to achieve a personalized strategy that achieves health and wellness. If population health and wellness is at the core of what health systems are mandated to address, then system priorities and measures of performance must be directly aligned to measuring outcomes based on articulated value. Only then can the existing gap be addressed between health related values held by a population and how the healthcare system is currently designed, organized, funded, and evaluated.

## **Philosophy and Personalization**

As exciting as the advances are in genomics and in technology that enables access to health information, it is important to recognize how these elements may shift how individuals and populations consider and use healthcare. Bioethics is a division of philosophy that examines questions related to the impact healthcare decisions have on people, to ensure that health services and technologies are not used in ways that violate human interests. Bioethics informs policy making as decisions are considered through the lens of how to achieve the best health outcomes that maximize human interests while minimizing harm. As noted by Arnason, "the benefits or damage that might result from personalizing medicine will depend no less up on political and policy decisions than on pharmacogenomics developments...moral issues must not be restricted to an evaluation of risk for individuals".<sup>4</sup> Bioethicists are on the whole in favour of personalized healthcare, but just as with any new healthcare technology, procedure, or policy, a philosophical examination of personalized healthcare has revealed a number of important criteria against which it must be measured including: achieving benefit and preventing harm; the importance of self-determination; and, justice and fairness in distribution of health services. We now consider each of these criteria individually.

### **1. Achieve benefit and prevent harm**

Health systems are challenged to allocate resources in a way that ensures the necessary technology is available when, and for whom, it is needed. They further must determine whether the new technologies and services achieve benefit and prevent harm. To do so, those controlling the access to expensive healthcare technologies must consider the socio-political-economic impact of the technology such as "privacy and consent, risk of harm or discrimination".<sup>5</sup> As an example, new technologies that are able to map the genome for individuals have substantial implications for health systems. How do health systems personalize their services to the segment of the population who need particular types of preventive, or risk mitigation therapies? Does the entire population receive genetic screening? How would individuals who do not want genetic screening "opt out"? How does the outcome of genetic screening observe privacy needs of individuals? At what cost, meaning what resources, have to be made available to pay for population wide genetic screening? What is the value proposition that genetic screening offers to populations? And what social-political- and economic impact would genetic screening have for individuals and their families (i.e. impact on seeking insurance, impact on workplace and employment). These are all questions that must be addressed through active dialogue between the population and the social and political structures that make decisions, to create a personalized health system.

Personalized health systems must deliver value to the populations they serve within the context of the unique social, political, and philosophical perspectives underlying the culture of each population. As such, the concepts of benefit and minimizing harm vary across global health systems and are dependent on the cultural context. As Arnason (2012) suggests, "the project of personalizing medicine can either increase or decrease health inequalities both globally and within individual countries. Which way it goes

will depend, in part, on political and policy decisions".<sup>6</sup> The key strategy for health systems is to engage the population actively in debating and determining these important decisions to achieve benefit, and reduce harm.

## **2. Self-determination (Agency)**

To achieve a personalized health system that delivers value to the population it serves, the principles of self-determination and agency implore health systems to look beyond the narrow perspective of disease management and consider how personalization can offer value for the whole population, not just those with illness and disease events in their lives. To begin, health systems must recognize that health and disease are determined by the interaction of any number of a broad range of socio-economic, ecological, historical, genetic, developmental, physiological, and cultural factors or determinants. Research has documented these determinants at both individual and population levels<sup>7</sup> and has further suggested that to date, medicine has not achieved the health outcomes that many, less expensive strategies have been able to achieve, such as environmental or social programs.<sup>8</sup> It is important to acknowledge that avoidable inequities in health arise because of the circumstances in which people grow, live, work, and age, and the systems put in place to deal with illness. The conditions in which people live and die are, in turn, are shaped by political, social, and economic forces.<sup>9</sup> A recent study on Canadian values concluded that the Canadian population values and aspires to achieve health, wellness, and quality of life.<sup>10</sup> Yet, the Canadian health system measures its performance on the basis of quality, safety, efficiency and cost of delivering health services, which is focused on disease and illness. A personalized health system needs to shift their mandate towards achieving value relative to what matters to people, wellness and quality of life. The issue of self-determination raised in the bioethical literature raises the question, "Who decides?" within a personalized health system.

Self-determination, the right to decide on what is best or most valued, suggests that personalized health systems must be structured to engage ordinary citizens to determine policy through public deliberation, with the help of experts to provide information and other feedback regarding inconsistencies in reasoning. In a personalized healthcare system, policy decisions must involve serious public dialogue involving (demographically representative) members of the public who negotiate with each other using good (consistent and with empirically accurate claims) moral reasoning.<sup>11</sup> Personalization at the level of the health system means a movement away from the paternalistic "doctor (or health provider) knows best" approach, towards a collaborative "what will best serve the personalized goals of quality of life and wellness of the population" model that is deeply embedded throughout the entire healthcare system. This collaborative model of personalization should be structured beyond the level of the individual-provider context to include the community-health organization context, and the regional/sub-population context in order to achieve meaningful outcomes for the population served by the health system. Inherent in this model is the need to engage individuals, communities, regions, and sub-populations so that they collaboratively make decisions on how health services will be personalized to support their unique values and health goals. Such decisions are complicated by the fact that the reality regarding who will benefit from different kinds of personalized healthcare is complicated as there is no "thick, bright line separating minimal responders from maximal responders... The reality is more like a ragged edge; some people will clearly benefit a lot, some people will clearly not benefit at all, and many people will benefit somewhat."<sup>12</sup>

How meaningful public engagement can be implemented, including how and what information should be provided, and how to point out errors in reasoning have been extensively studied and discussed by sociologists.<sup>13,14</sup> Public engagement has played out in practice in a variety of ways that are relevant to

the social and cultural context of different countries and their population, including polling techniques, citizen workbooks, and citizen dialogue using panels of representatives of different subpopulations (i.e. Romanow commission).<sup>15,16,17,18</sup> Public dialogue must also consider the question of whether individuals and other private entities (such as companies providing extended health insurance for employees) have a responsibility to provide personalized healthcare technologies in order to keep individual/community/population healthy. Public dialogue must also consider if, within these private groups or enterprises, the use of personalized healthcare technologies is the best way to maximize the attainment of human interests. These are not easy conversations to have; public dialogue that supports self determination to delineate how this is achieved will be central to a personalized healthcare system.

The traditional health system in many countries could be characterized as patriarchal; health system leaders determine the allocation of resources to deliver health services and health provider teams determine the best treatment and therapy options for the patient populations they serve. The shift from top-down control to collaborative decision-making requires that individuals, communities and populations collaborate on how health systems are structured so that they are meaningful and achieve value for the populations they serve. This collaborative model will require consumers, communities, and populations to define their role and responsibilities in personalizing strategies and services to achieve health, wellness and quality of life, rather than relying on the traditional medical model of most health systems that assume responsibility and make decisions on their behalf. This is a significant realignment in thinking for citizens in most populations, and a very significant change in how health system decisions are designed and implemented to achieve value. The most important feature of personalized health systems is that citizens can exercise self-determination and have input into defining the value health systems must deliver on, that is focused not on each individual citizen (which is untenable), but on delivering value to the population it serves. To achieve this, personalization must reach far beyond disease and risk management, and aspire to focus on quality of life, wellness, and the social determinants of health that achieve value.

### **3. Justice and fairness**

A significant lens through which the field of bioethics considers the distribution of healthcare resources is justice and fairness. In many health systems, fairness and justice is related to access to care. Hoyer et al.<sup>19</sup> have shown that genetic research participants in Scandinavia find it very important that the resultant studies are used to benefit society, to do so fairly, and to benefit science as a whole.<sup>20</sup> Similarly, empirical research on what Canadians value most in their healthcare systems indicates that that timely access and quality/comprehensiveness are the key priorities that health systems must achieve.<sup>21</sup> The notions of quality and comprehensiveness in a public healthcare system imply quality and comprehensiveness for all, as no one would say that a public healthcare system was comprehensive and/or of high quality were a significant portion of the public unable to access quality healthcare.

Accordingly, this principle of justice as fairness, that "unequal distribution of social goods is justifiable only insofar as it benefits the worst-off"<sup>22</sup> forms part of the historical foundation of modern thinking in bioethics. Even when not necessarily explicitly referenced, Rawls's "justice as fairness" either forms the theoretical underpinning of,<sup>23,24</sup> or is being extended, modified, or improved in, contemporary bioethics literature. Rawls's remains the major theoretical touchstone of much work in ethics, including bioethics. Fairness must necessarily involve the creation of healthcare policy based on what decisions would be made when stakeholders from all relevant demographics are consulted and their recommendations are considered when establishing policy.<sup>25</sup> Values of fairness and equity require that every citizen has the same access to health services. In many countries, universal access to healthcare is ensured for all

citizens by legislation. While equity in access to care does not necessarily "personalize" a health system, it is a necessary condition that matters to most populations around the world given the central importance of healthcare to the quality of people's lives.

Increasingly, the concept of justice will be an important lens through which to view personalization of health systems. Personalized medicine has the potential to divert health system resources to expensive and high-technology strategies for curing disease and illness which, in socialized health systems, limits the funding available for other services and procedures. Issues of community relevance and access are critical features of personalized health systems;<sup>26</sup> the challenge will be to spark the significant shift in thinking that must take place to more conceptually and organizationally from the traditional biomedical model of healthcare focused on disease care and management, to a personalized health system that achieves value for the population focused on wellness and quality of life.

### **Role of Research in a Personalized Healthcare System**

Healthcare is a knowledge intensive system that relies on complex models of research to discover, test and implement new approaches for achieving value for populations. A personalized health system will continue to be married to the translational research model in order to understand best evidence for the impact of strategies to achieve personalized approaches that deliver value for populations. One of the important challenges for research communities will be the need to shift from a dependence on clinical trials research that is typically disease specific, to a more values-based translational model that examines the impact of personalized health system approaches designed to fit with population values. Without tangible evidence, health system leaders will continue to be challenged to make decisions to consider leading new approaches to personalizing healthcare. There is a danger that we may pursue omics and telecare because those responsible for distributing dollars find the technology exciting even when there are more efficient and just ways of increasing the health of the nation.

Translational research focused on value-based outcomes will need to bring a new perspective on evidence to guide and support policy structures for a personalized healthcare system. What is required to accomplish this shift is a process of rational deliberation, where the best evidence and most reliable methods are used to shape and inform public understanding and judgment, rather than self-interest of influential stakeholders in health systems.<sup>27</sup> The public needs to engage in a transparent and impartial dialogue to better understand the ethical and economic challenges of delivering healthcare services that create value within limited fiscal resources. It is only through this public dialogue that communities and countries will be able to accelerate the transformational shift required to move from the traditional, top-down healthcare model, to one that introduces personalization in a rational and considered way that protects ethical boundaries, treats populations fairly, and delivers individual and population goals.

## Section 2: The Emergence of the Empowered Consumer

There is increasing evidence that not only are individuals ready to manage their own health and wellness, they are actively seeking out strategies and tools to take charge of their health and to change the way they access health services. Globally, access to information and online tools are more widely available than ever before which is not only changing how information flows, it is changing how entire populations are seeking and engaging in health and wellness. People are seeking out digital tools, online resources, and advanced communications technologies that are most often external to the formalized health system, including virtual patient forums, mobile health applications, self-help programs, monitoring, and tracking. Digital communication technologies have advanced rapidly, providing consumers with unprecedented access to health information. Online "self-help" videos (such as those available on YouTube) now offer a virtual library for consumers to independently learn and study a procedure or therapy, or learn about a condition. Consumers have the ability to review videos on health information repeatedly, as many times as needed, to fully understand the information they need to effectively self-manage their health. The use of these online tools and resources are allowing entire populations to create their own personalized model to self-manage their health and wellness, usually independently of formalized health systems. This emergence of the empowered consumer is one of the most significant changes to healthcare in recent years.<sup>28</sup> It is re-shaping health systems from "outside in", where consumers now come equipped to health teams with information and toolkits creating a very different interaction with health providers or health teams.

The rapid evolution of information and communication technologies has also been identified as one of the most significant enablers of health system innovation.<sup>29</sup> However, health systems are by and large disconnected from this personalized health and wellness platform for two primary reasons. First, health systems focus primarily on managing illness and disease, rather than focusing on health, wellness and quality of life.<sup>30</sup> There is a poor fit between what formal health systems have to offer (i.e. disease management) and what empowered consumers value and are seeking to achieve (i.e. health and wellness). The second reason is that the majority of digital tools and platforms available online to consumers are not connected or interfaced with the formalized health system. Although consumers are actively using personal health tools online, there are few opportunities, if any, for consumers to link their personalized health tools to the formalized patient health data embedded in health systems. Essentially, what has now emerged are two, almost completely distinct and separate healthcare systems. One is the traditional healthcare system which is often institution-centric and provides services to manage illness and disease. The other is the consumer-based system within which people select and engage online tools and resources to personalize their own system of health and wellness that is custom-made to the needs, values, and goals of the individual.

The purpose of our analysis of the engaged consumer is to better understand what drives consumers towards these personalized approaches to health and wellness care, and to examine how the momentum of this personalized consumer movement can be leveraged by health systems to achieve value for the populations they serve.

### **What Drives Consumers to Personalize Health and Wellness?**

There are a number of drivers that are motivating and influencing the consumer desire to take control of and find tools that allow them to manage their own health and wellness. We explore seven of them below.

## **1. Drive to learn and better understand health and wellness**

In today's society, consumers are empowered to pursue value in decisions about their health and healthcare, more broadly.<sup>31</sup> Why? Because consumers do not want to wait to get sick before they are able to seek healthcare services, they are driven to achieve health and wellness. This is a major value proposition for consumers worldwide which is supported by recent research. A 2013 report released by Pew Internet and the American Life Project Study found that 72 percent of American internet users were already seeking health information online.<sup>32</sup> Within the online channel, mobile phones are becoming an increasingly important delivery mechanism for health information. With 85 percent of adults in the United States owning a cell phone (over half of which are Smartphones), it is not surprising that of all cell phone users, approximately a third have used their phones to look for health information with that number rising to slightly more than half (52 percent) when one only considers Smartphone users.<sup>33</sup> There is clearly an increasing trend on the part of consumers to use mobile technologies to access health information.

The increase in online mechanisms to access health information is only fueling this demand, and the explosion over the past five years in the use of health applications on mobile technologies is a clear indication that this desire is only growing as individuals discover the tools available to them to increase their health literacy.

## **2. Drive to engage and connect to other consumers**

People are actively engaging others by creating online "communities" composed of people who are experiencing similar health challenges. This type of online peer to peer support is offering consumers the opportunity to learn from "people like me", which assists them in managing or achieving the health goals they all have in common. Although there is limited evidence, the use of peer communities may also be a strategy for validating an individual's personal experience with health treatments, therapies or procedures, to ensure they are reaping the same benefits others have experienced. Online communities of peers focused on supporting each other to achieve health goals may also offer people the confidence of comparing their progress with that of others, which will further inspire them to work towards their goals. Individuals are also engaging broader groups through mechanisms such as crowdsourcing, where information is solicited from the mass population in response to healthcare questions, especially for diagnosis or second opinions. While the validity of the medical information provided through these methods may not be considered "evidence based", people often consider the experience of others as important evidence to consider when making their own health decisions. This ability to create or join online communities or request information and advice through crowdsourcing are especially valuable for people who have geographical barriers or financial barriers to accessing health services or specialized practitioners.

## **3. Drive to "Take Control"**

People naturally strive for self-determination. They choose to make their own decisions, work to achieve what is best for their personal goals and values, and strive to determine their own destiny. Traditionally, health systems have been structured in a top-down way in which decisions are made by health professionals, care and treatment is prescribed/handed down based on pre-determined best practice or best evidence, and people are expected to "comply" with prescribed therapies. The value proposition these traditional systems offer is limited to prescriptive disease management services.

Yet, people inherently strive to self-determination of what is important to them, what matters in terms of their individual health and wellness journey, and how they can take control to achieve personal health

goals. With the explosion of sophisticated information technologies, people are aggressively seeking ways to become active participants in their personal health journey. New technologies are enabling that engagement in ways that would have been unheard of a mere decade ago. Patients are no longer waiting for information to be given to them by their care provider; they are now taking initiative, to look for and use information pertinent to their individual health circumstances to assist them in understanding what is currently happening to them, and what is likely to happen in the future. This quest for information is being supported by private sector health ventures operating outside the traditional health system paradigm. As an example, a new United States-based information technology company called Medivizor takes information from patients including their condition, stage of disease, treatments they are on, medications, and underlying conditions, and delivers information regarding the disease and relevant clinical trial notices.<sup>34</sup> Patients only receive information that is relevant to them, significantly reducing the volume of health information they have to go through. There are numerous digital tools and online services which have now clearly engage and enable consumers to take control, define health and wellness in their own way, and set out to achieve their personal health goals. This emerging trend will undoubtedly influence health systems and the life sciences market. Frist suggests that if only 10 percent of the population begins to seek value in the care it receives, the health sector will have to respond positively to the benefit of the other 90 percent.<sup>35</sup> Through their desire to become more educated, enlightened consumers will drive physicians, hospitals, clinics, and health organizations to restructure, focusing on providing quality care that is personalized to the needs and values of the population they serve.

#### **4. Drive to "Self Manage" health information**

There is no question that consumers today are seeking and striving for health information that is relevant to them, is easily understood, and is actionable. Consumers are demanding access to information that is relevant to their personal needs and links to their desired health outcomes. Consumers want to fully understand all of the possible treatment or health program options, the associated risks and benefits for each, so that they can make informed decisions about their health and wellness. The challenge is that health systems have always been structured to ensure providers have access to patient information and records, with little opportunity for individuals to have access to their own health information. Essentially, health information has always been very health system focused and provider-centric, rather than consumer-focused and easily accessible to the very individuals upon whom the information is based.

The drive of consumers to acquire and manage their own personal health information is starting to emerge, in large part due to consumer drive to self-manage and achieve value. This trend has grown exponentially in recent years as information technologies have revolutionized the automation, connectivity, decision support, and mining of health information and data that are expected to radically transform health service delivery.<sup>36</sup> There is an emerging trend towards using technologies to provide people personalized health information through online access to their health records and lab results that also connect with physicians or healthcare teams. Providing people with their personal information about their medical data increases health literacy and at the same time enables consumers to better understand their health status as it changes over time. People who have access to their health information prior to appointments with health providers have the ability to shift the patient-health practitioner dialogue to a conversation that is more informed. In fact, people are growing increasingly intolerant of providers who "hoard" information, keeping it from the very person who needs it to make informed decisions. There is anecdotal evidence that consumers now bring a list of questions from "Dr. Google" to provider appointments to ensure they are asking all the necessary questions required to make informed decisions. In some cases, providers have now limited office or clinic visits to "three questions only" to manage the time pressures these "Dr. Google" demands for information

are creating, a symptom that health systems are ill-prepared for actively engaging empowered consumers.

## **5. Drive to ensure accuracy**

People who have access to, and manage, their own health information are more likely to recognize changes or error in health data. Given the self-interest demonstrated by patients in their personal health information, any anomalies in diagnostic tests may be discovered more quickly; this can be important given that seven percent of abnormal lab results are not communicated to the patient and improper follow-up can result in inappropriate or delayed diagnoses.<sup>37</sup> Being able to access doctor's notes when a patient finishes an appointment helps minimize the possibility that a person might forget or misunderstand instructions when they rely solely on a single interaction with health providers. Now there are online tools and platforms available at a low cost to help individuals manage their personal health information more easily. Not only will this assist with ensuring accuracy in terms of the recording of health-based information, these tools facilitate the collection and recording of health information at the individual level, potentially creating the ability to more effectively manage choices that will directly impact health and wellness. This trend will be particularly important for health systems given that the most important and influential driver of health status is individual lifestyle behaviour.<sup>38</sup> Currently, the most significant challenges health systems face globally is the growing prevalence of chronic illness due to lifestyle behaviours (i.e. obesity, smoking, alcohol). By making it easy to track personal data, patients can witness firsthand what triggers their adverse health effects, making the link between actions and health outcomes more tangible, inspiring them to actively monitor and track their progress.

## **6. Drive to collaborate with health providers, not be simply recipients of care**

Empowered with access to information, consumers are striving to create a new dialogue with health providers. Communications strategies that link people to their care team are being built into new technology platforms, enabling the potential for information sharing from both the patient and the provider in ways that were unthinkable twenty-five years ago. These technologies create an opportunity for consumers to achieve greater connectivity for ongoing engagement with health providers, creating the conditions for shared decision-making.<sup>39</sup> There are many ways this can occur. In the United States, almost half of healthcare consumers are open to receiving medical care between visits via email, while 85 percent felt that emails, text messages and voicemails are as helpful, if not more so, as an in-person or phone conversation with health providers.<sup>40</sup>

Numerous providers are now employing online tools to more readily connect with people. Online healthcare services are not only engaging directly with people using email, many physicians are using social media tools to provide information to the general public to support health and wellness to the population. Examples include a Canadian physician who uses a web channel on YouTube ([www.youtube.com/docmikeevans](http://www.youtube.com/docmikeevans)) to provide the public with "a medical school" complete with health videos that have been viewed by millions of people worldwide. There are numerous online health services emerging where people can access physician and specialist care at their convenience (i.e. [www.medeo.ca](http://www.medeo.ca); [www.onlinedermclinic.com](http://www.onlinedermclinic.com)). Online tools are being used by a growing number of physicians to reach out and connect more efficiently with patients, including widespread use of telehealth, home health programs (i.e. the "Medical home"), videoconferencing with specialists for referrals, and even an online model that provides remote intensive care specialists to rural hospitals.<sup>41</sup> These technologies demonstrate evidence

that health providers are beginning to use digital technologies to reach patients more efficiently, particularly in remote settings. This trend is likely to continue to grow as much more informed health consumers will continue to strive for a deeper engagement with the healthcare team of their choice.

## **7. Drive towards consumer engagement**

Health systems are being challenged to respond to the rise of discriminating healthcare consumers, who are demanding to be involved in decisions about treatment, and empowered with choice in flexible, responsive and patient-centered healthcare services. This consumerism, or need for consumer engagement, is closely linked to a growing health literacy as consumers can now go online to access expertise and knowledge from around the globe. The phenomenon of "Dr. Google" is more than just the availability of and access to online technology. It signals the desire to take control of one's health and wellness using mobile technologies, witnessed in the explosion of health applications for mobile phones and computer tablets and technologies such as the Apple or Android operating systems. The desire for greater personalization was also evidenced in a 2012 Deloitte Survey of US Health Consumers which found that a majority of respondents (57 percent) were interested in creating plans that were specific to their needs rather than relying on pre-defined options.<sup>42</sup>

Responding to the trend of the empowered consumer is challenging for health systems as it has the potential to undermine the hegemony of the medical model of health, where there are established traditions of professional dominance and the requirement that professional judgments of clinical 'need' be considered above the 'wants', 'preferences' or 'choices' of patients. However, healthcare consumerism is much less about, what some may view as, responding to limitless consumer demands for services and technology and the preponderance of an entitlement mentality, and much more about enabling patients to make informed treatment choices and set priorities for their own healthcare agenda, providing the public with information about health and healthcare quality, respecting rights to privacy, enhancing health literacy, and, with expert guidance from healthcare professionals, helping people understand what is necessary versus what may be discretionary. Ultimately, healthcare consumerism is about finding ways to support people to make informed decisions about what is best for their personal health and wellness.

### **Consumer Use of Health Apps to Achieve Personalization**

There is no question that the rapid evolution of the mobile application market, dominated by Apple (iPhone) and Google Play (Android), has become one of the most influential drivers of personalization of healthcare for consumers. There are currently more than 97,000 mobile Health applications, 42 percent of which are paid apps, listed on 62 full catalogued app stores worldwide.<sup>43</sup> In the last year alone, there was 134 percent growth in mobile users viewing health content on their mobile devices, the highest of all content categories.<sup>44</sup>

The explosion of health applications (health apps) accessed easily and efficiently using mobile technologies provides important insights for health systems into the ways consumers are driving personalization of health services. The figures related to usage of apps are staggering for a market that only debuted in 2008. Research conducted in 2011 predicted that by 2012, there would be 44 million health apps downloaded, with that number expected to grow to 142 million in 2016.<sup>45</sup> Global

revenues for mobile healthcare applications were predicted to reach \$1.3 billion in 2012, up from \$718 million in

2011, and expected to reach \$26 billion by 2017.<sup>46</sup> The rapid growth in the use of health apps may offer important trending and insights into how consumers are using these apps and what the purpose and intent the app is designed to achieve, in order to consider how health systems may engage or leverage consumer's personalization of health services.

In order to better understand this phenomenon, researchers at the International Centre for Health Innovation at the Ivey Business School at Western University performed an analysis to examine the current state of the mobile health app market. The following research questions were asked:

- Which health apps are the most popular?
- What do these health apps do?
- How are consumers using these health apps to achieve value?

To begin this analysis, the Apps lists were generated for iPhone and Android from June 4<sup>th</sup> - June 11<sup>th</sup>, 2013. According to GooglePlay, the Android app store, Top 100 lists are generated multiple times per day based on an app's recent download numbers and user ratings. Lists were generated for "Top 100..." of each type of health app as outlined in Table 1.

**Table 1: Source of "Top 100" Health Apps**

Platform	Type of App	Total Number of Apps in Category
GooglePlay (Android)	Free Medical	5, 720
GooglePlay (Android)	Paid Medical	2,463
GooglePlay (Android)	Free Health and Wellness	15,232
GooglePlay (Android)	Paid Health and Wellness	4,106
iTunes App Store (Apple)	Paid and Free Medical	19,690
iTunes App Store (Apple)	Paid and Free Health and Wellness	24,226

As noted in Table 1, there are two broad categories of health apps: health and wellness (including fitness); and, medical. The vast majority of current health apps focus on general health, wellness and fitness programs or tools that allow users to track biophysical health indicators over time, and apps that simply offer basic health and fitness related information. According to a 2012 report by the Pew Research Group of consumers in the United States, most "healthcare" apps are used for the purposes of tracking fitness (38 percent), tracking diet (31 percent) and tracking weight control (12 percent).<sup>47</sup> This study further found that 19 percent of Smartphone users had downloaded some kind of health app that assisted them in managing or tracking their health.

User categorizations have divided apps into groups according to the dominant users for the app, such as apps designed primarily for consumers/patients as compared to apps designed and used primarily

by health professionals. It is predicted that 15 percent of global mobile health apps are designed for healthcare professionals, not surprising given that 80 percent of physicians surveyed in the United States owned a mobile device with 30 percent of physicians reporting using a smartphone and/or tablet to treat patients as of 2012.<sup>48</sup> The types of apps targeted to healthcare professionals include reference apps that offer the most current information on diagnosis, lab test values, disease classifications, assessment tools, medication dosing references, remote monitoring tools, and healthcare management applications.

## **Analysis of Top 100 Apps**

In the analysis conducted by the International Centre for Health Innovation, the top 100 most popular apps (based on a combination of download frequency and user rating) were identified and analyzed using a simple content analysis to define the purpose of each app for consumers in order to identify the major themes across apps in terms of what the apps are achieving for and with consumers, and to examine the value these apps may be offering consumers outside of traditional health systems. The top 100 apps lists were generated for both Android and iPhone, categorized by: paid versus free; and medical versus health and fitness. The top iPhone 100 app lists were created for both Canada and the United States. These lists generated 1200 apps in total which were subjected to content analysis.

The first level of analysis compared the diversity in types of apps for similarities and differences to determine whether the type of app (Android or iPhone) varied based on the choice of platform. We found the types of apps were similar across both platforms with only minor variation. The next level of analysis examined the types of apps for each of the types of platforms categorized into "health versus medical" apps and then "free versus paid" apps; this created eight different categories. In all, 1200 apps were reviewed and subjected to a content analysis using the app description as the unit of analysis to examine the intent and value the app offers to consumers. This analysis was based on a number of assumptions. It was assumed that if the app was downloaded then the consumer was using the app for the purpose it was intended. The second assumption was that for the most highly downloaded apps, the activity or purpose of the app offered insights into what consumers value in terms of personalization of health and wellness.

Each app list was then reviewed to identify the major themes across apps. The themes were startlingly different for apps that were designed for health professionals, compared to apps designed for consumers. The themes across the consumer based apps were clearly and almost exclusively focused on health and wellness behaviours, primarily for the purpose of self-management. The apps for health professionals were primarily focused on diagnosis and treatments, evidence-based practice, and information on anatomy and physiology.

The content analysis of the apps used most heavily by consumers revealed four primary strategies consumers are engaging to achieve a personalized approach to health and wellness. The first major theme was tracking and monitoring. These are apps that simply enable consumers to track specific biophysical or behavioural measures to map their progress towards specific health goals. Examples included using apps to track calorie intake for dieting, measure the distance people are running, and record heart rates/blood pressure. There were no monitoring or tracking apps noted for health professionals; however, there may well be such tracking tools on more sophisticated office software or digital platforms used in health teams or organizations.

The second theme in the consumer use of apps is best described as "personal coach and trainer" apps. These are apps that offer the consumer training or instructional programs to assist and support managing

lifestyle behaviours to achieve health and wellness. Coaching programs included dietary management, sleep enhancement, meditation techniques, stress management therapies, and exercise programs. The most impressive feature of the coaching and training apps was the broad range of training programs and the diverse focus of these apps on a wide variety of health and lifestyle behaviours.

The third theme in the consumer use of apps was best described as "decision support" apps which are notable as these apps provide consumers with a wide variety of information to support decisions about health and wellness. For example, there was a large amount of women's health related information that offered insights and information to support healthy behaviours related to pregnancy, teaching women about the phases of pregnancy and how to make good decisions to achieve a healthy pregnancy and a healthy newborn. Similarly fertility apps informed couples about decisions on how and when to successfully achieve pregnancy. Other decision support areas of focus included information about health wellness such as sleep cycles, diet and exercise. Very few apps were designed for specific disease management decisions such as diabetes and managing headaches. These decision support apps comprised less than five percent of all of the top 100 apps downloaded by consumers.

The majority of apps in the analysis, whether they were paid apps or freely downloaded were designed for the consumer. Only 21 percent of the most popular apps downloaded were designed for health professionals (n=263). Without exception, the medical apps were focused primarily on diagnosing or prescribing described interventions for disease or illness conditions. The medical apps most often downloaded by health professionals can be captured in three categories:

1. Diagnostic and clinical intervention apps: Apps which provided references for diagnostic testing and prescribed therapies. These included apps that provided normal ranges of lab values, described doses for medication or listed current medications.
2. Best practice apps: Apps that offered references to research or clinical trials on specific therapies, drugs, and practice protocols.
3. Anatomy and physiology apps: Apps for the new health professional to support learning anatomy and physiology.

Our analysis revealed clear differences in the apps used most heavily by consumers and the apps in use by health professionals. The widespread use of apps by consumers is focused on self-management of personal health and wellness. Consumers are readily able to download apps with a medical focus, such as diagnosis or disease; however they choose to focus their efforts on personalized programs, tools, and strategies to self-manage their health and wellness.

### **Additional Research on Health Apps**

Our results are similar to those found in other studies. Verasoni Worldwide created the AhHa! Insights 2012 Mobile Health Application Study that compared the top 150 downloaded Android and iPhone mobile health apps in the United States.<sup>49</sup> The study found that the top three categories for health apps downloads included weight loss (31.5 million), exercise (11 million) and women's health (7.5 million) for iPhones, and weight loss (18.5 million), exercise (15.5 million) and tools (8 million) for Android devices. The top three categories for paid health apps (based on the number of downloads) were sleep and meditation (2 million), exercise (1.8 million) and weight loss (1.6 million) for iPhones and exercise (350,000), weight loss (205,000), and tools and instruments (110,000) for Android platforms. When you look at the total downloads across both platforms, weight and exercise comprise approximately 60 percent of all downloaded health

apps, with the vast majority being free rather than paid. This finding was supported by a 2013 study by Ruder Finn which found that the top three categories of health apps used by consumers were healthy eating apps (49 percent), fitness apps (48 percent) and calorie counter apps (48 percent).<sup>50</sup>

## **The Appeal of Health Apps**

There are a number of immediate benefits to health apps beyond just their convenience, ease of access and often low cost for the consumer. Health apps and mobile technologies empower people to self-manage their personal health and wellness to achieve what matters to them - quality of life. Health apps also enable a more personalized or tailored approach to health and wellness which may result in better health outcomes at the population level. The appeal of the use of health apps is undoubtedly the convenience of having a personal "health coach" in the palm of one's hand, along with ready access to decision support tools to support people to make health decisions, armed with the best available information.

Finally, health apps provide a way for people to engage in their health that is consistent with social norms. The average smartphone user checks their phone 127 times a day; given the norm associated with cellphone use, it becomes more discreet for people to use mobile health technologies to monitor health behaviour as it is easily integrated into the routines of day to day life. Imagine the formalized health system and the inconvenience of arranging an appointment, waiting to see a health provider and having to leave work, or day to day routines in order to access care. It is very possible that mobile health offers the impressive opportunity to engage healthcare services, in real time, at the convenience of the individual person, rather than at the convenience of health providers as is currently the routine in health systems. Just one example of the appeal of the use of health apps is reflected in a study of patients with diabetes who report their preference to use their smartphone to manage their condition rather than an insulin pump because in checking a cellphone, they are doing something that everyone around them is doing.<sup>51</sup>

## **Why Aren't Health Systems Engaging and Adopting Health Apps?**

The explosion of health apps offers a golden opportunity for health systems to engage consumers using tools they are already familiar with and accessing on their own. To date, the explosion of mobile apps by consumers has the potential to evolve into a personalized, consumer driven healthcare system, complete with social networking platforms to engage peers, experts, and health services worldwide. Currently, formalized health systems run completely parallel and exclusive to the consumer health system. The question is why are health systems so slow to engage and leverage consumers' drive for personalization of health services focused not on disease, but on health and wellness.

One of the barriers to the widespread adoption and impact of health apps is the privacy, security and liability related to accessing health data that consumers upload or input into health apps. Health information is considered highly sensitive and private, and there are valid concerns regarding liability should inappropriate access to information take place, or if health information is inadvertently released due to technical issues. There are often ineffective protections placed around who is able to access the app from both a provider and consumer perspective. There are also questions around the assessment and potential regulation of apps, particularly if they are being used in a clinical context. Currently, the FDA in the United States has released draft guidelines for industry and for FDA staff on the regulation of mobile medical applications, indicating some future mobile health apps will require FDA approval, specifically those that interact with currently regulated mobile devices.

Another barrier is the capacity of existing systems to cope with two fundamentally different processes within a single system. 20th century evidence based care encourages concordance, and personalization makes this more complex. Most health systems lack the capacity (as well as the capability) to do both concurrently.

Health systems are knowledge intensive and rely heavily on empirical evidence before the adoption of new technologies and innovations are even considered. The rapid development of 47 million health apps in just the last 5 years is unprecedented. Thus, it is difficult to get evidence on the impact of an app when it has been available for such a short period of time, and it is challenging to measure the impact of apps on health outcomes when the technology used is constantly evolving. A study published in the Journal of Medical Internet Research noted that outcomes of mobile health have barely been documented.<sup>52</sup> The study could not find a single scientific paper published through early 2012 that evaluated a smartphone app in general release through an app store, just a few pieces of software developed for research purposes.

While the challenges surrounding health apps and the use of mobile technologies as healthcare enablers must be addressed, it is clear that the advent of these tools in the health sector has the opportunity to revolutionize healthcare globally. Health systems need to find ways to meaningfully engage consumers through the use of apps to ensure that the convenience, the "real time" nature of app based tools, are built into the system to achieve the same value that apps have achieved – to access health services and resources at the convenience of the person, not the provider or health system. Apps offer an impressive range of health and wellness tools that are designed to be easily accessible and understandable, providing global health systems with important, low cost tools for delivering health services more effectively in a consumer-centric model. These app technologies can not only change how healthcare is delivered, they hold the potential for the rapid dissemination of health innovation with the goal of improving patient outcomes, and delivering on the value proposition to the populations that health systems are designed to serve.

## Section 3: Personalization in Industry: What Can Health Systems Learn?

Healthcare is predominately designed and implemented at the system level with a "one size fits all" perspective, with little thought given to patient preferences and values. In many respects the business model in healthcare has changed little since the 1950s. It is still based on the "office call" as the medium by which care is delivered and this is both highly inefficient and difficult for the people to access in a way and time fit for the 21st century. Currently, there are few opportunities for patient choice and input into clinical, service and operational decisions. Services are not tailored to individual needs or preferences, sometimes creating a disparity between patients. If health systems were to design strategies to better understand consumer preferences or decisions related to health and wellness, health systems would be able to reach well beyond the dominant disease-diagnostic approach to service utilization and consider a more value-based approach to healthcare. Understanding what consumers appreciate and desire, what decisions and choices they make regarding their health, are the first steps to designing personalized health systems that achieve value.

Given the lack of healthcare innovation on this front, there is an opportunity to look to other industry sectors and examine successes in fostering consumer choice while not adding to system costs, and determine whether there is an ability to adapt and translate these successes into healthcare contexts. We present three "lessons" that healthcare systems can learn from industry when it comes to personalization, providing examples from various industry sectors and organizations of successful application and implementation.

### **Lesson One: Use consumer preference to achieve personalization.**

Personalization is a common strategy that has been employed by many industry sectors to achieve a competitive advantage and increase market share. It is remarkable when one considers that the very same populations that health systems serve are simultaneously supplied by industry sectors such as banking, travel, automotive and retail shopping. To date, health systems have only embraced personalization strategies in a very limited way suggesting there are successful customization practices that have been employed for decades by industries outside of healthcare which may offer important insights into the way forward for the personalization of global health systems.

There are three strategies that industry uses to understand consumer preferences and values that inform industry's strategy to "personalize" and strengthen customer experience. These include: active, passive, and progressive personalization. Active personalization is a strategy that enables consumers to make choices to meet their needs, such as placing a specific order for a product or service. In this strategy, consumer choice is used to understand consumer preferences and values that enable an industry to "personalize" their products and services. The analysis of mobile applications to support self-management of health and wellness is an example of how consumers are personalizing their healthcare, selecting specific tracking and monitoring programs, engaging decision support resources to inform their decisions and using personalized coaching to achieve health and wellness goals based on what matters most. Active personalization using mobile apps has occurred largely outside of formalized health systems. One opportunity for health systems is to engage active personalization by creating opportunities for consumers to link their personalized programs and tools (i.e. mobile health tools) to formalized health systems so that health providers or teams can collaborate and partner with

consumers to achieve their health goals. This opportunity also holds the potential to provide health teams with valuable information about the individual's health and wellness goals, to personalize care approaches more effectively. We expand on this idea in our recommendation section.

Passive personalization is the second type of strategy that industry uses to personalize experiences for their customers. Industry gathers information about customer patterns (i.e. their purchases) to better understand what customers want, how they want to engage or be served, and to link or match a product with a user demographic or typology. Software analytic programs are used to monitor user preferences, analyze them and then industry uses this "passive" market intelligence in targeted marketing campaigns that are "personalized" to particular sectors of the population. Health systems do not use passive personalization tools although they do track utilization of health services to understand patient volumes, frequency and prevalence of health services utilization. However, most utilization data is acute care centric given that health services in communities are not as well documented or tracked using utilization approaches.

Finally, progressive personalization in industry seeks or obtains consumer feedback in order to improve products as the consumer uses them, or as consumer feedback is obtained. There are countless examples of "consumer surveys" or telemarketing strategies that a variety of industries use to better understand the value proposition for consumers. For example, the travel industry uses "Trip Advisor" to seek customer feedback on travel experiences. Often before a person completes a vacation, an online survey is sent to the customer to obtain feedback on how to improve the services. While progressive personalization is a well-established practice in many industry sectors, healthcare has not embraced these methods to anywhere near the extent evident in other industries. An obvious and immediate application for health is patient satisfaction or patient experience survey tools. While health systems globally have identified patient experience as a system priority, patient satisfaction tools are limited to obtaining feedback on specific care transactions, most often in hospitals. Even in these scenarios there is often a long lag between when the consumer provides the requested feedback and when it is accessed and responded to. There are few, if any, examples of progressive personalization strategies that seek feedback relative to consumer choice, preference, values, and health and wellness goals, even at the level of a health organization. Yet, if health systems were to learn from industry's use of progressive personalization, health systems would be informed much more directly about what people value, and what matters to them, so that health services and approaches to care can be tailored to offer real value to the populations they serve. Simple technologies such as those used for "Trip Advisor" or mechanisms such as creating, publicizing, monitoring and immediately responding to a twitter hashtag related to customer feedback, might offer health systems an important place to start to achieve personalization based on customer preferences.

How can these three types of industry strategies inform health systems to achieve personalization? In many publicly funded health systems, consumers have few choices in terms of where they seek health services or who they can access in terms of care providers. Many countries organize services based on volumes so that resources such as hospitals, primary care clinics, or diagnostic services are available in urban settings to offer the greatest access to the most people possible. One of the few opportunities to gain insights into consumer preference and value may be the use of active or progressive personalization tools to better understand the values and needs of the population. This knowledge can then be used to personalize how health services are organized, structured, and delivered to achieve value based on first-hand information from the people who will be accessing the services.

The reality is that systems at present are overstretched with demands of an ever more complex and aging population and with more multiple morbidities. Medical science has added years to our life span but not done as well when it comes to add life to the years we live. The period of disability and less than optimal health has increased where it now takes up a far greater proportion of our total life span. This means the systems we have cannot introduce new ways of working as well as continue to provide what they do now.

The analysis of mobile app use is one strategy for examining opportunities for personalization based on customer preference. With current technology, the ability of online tools to provide customization and personalization for web-based products and services is unprecedented. Tools such as data mining, statistics, artificial intelligence, and rule-based matching are popular for building recommendation systems.<sup>53</sup>

The analogues for healthcare may include using online tools such as search engines and algorithms to increase access to health systems by helping people locate nearby practitioners, healthcare facilities, specialized services, and drug stores/pharmacies, or give patients and their families/caregivers information that is tailored to their personalized needs (i.e. using artificial intelligence modeling). There is substantive evidence that consumers are selecting, paying for, and engaging mobile apps to manage their personal health and wellness goals, but this evidence suggests that there are few, if any, interfaces between the personalized health systems of consumers and the formalized health systems in most countries.

Personalization strategies from industry may allow health systems to better understand value from the perspective of the populations they serve. A better understanding of population values and preferences may also enable designing health products, services or procedures to achieve greater relevance and meaning (i.e. "what matters) for people. Personalization based on consumer preferences could transform acute care services to focus on an individual's personal health and wellness outcomes rather than the limited focus on the transactional, curative outcomes, focused only on an illness or disease. Personalization that strengthens a person's experience and links care services directly with consumer health and wellness goals, would offer health systems an important way forward to achieving a personalized health system, capable of delivering value to populations. The following are industry examples of personalization from diverse industry sectors that may offer important insights into strategies health systems may consider.

### **Organization Example: Disney's personalization of consumer experience**

Disney has entered the realm of personalization with new methods to customize their theme park experience for visitors, using a range of information gathering systems. Recently they have created MagicBand bracelets with RFID technology. The band allows Disney guests to make purchases (it is linked to a credit card), but the band also serves as a hotel key, acts as a ticket for theme park admission, gains admission to VIP experiences, and stores Fast Passes to access rides. The band also allows for personalized interaction with Disney characters; for example, robot characters greet guests with personalized greetings such as, "Happy birthday, Alexander". The band is linked to a new app called My Disney Experiences where users can book hotels, make dining reservations, buy park tickets and pre-select ride times. For Disney, there are multiple benefits. Not only does it put decisions in the hands of consumers, freeing up the need for staff resources, it provides customers with a variety of choices so they can customize their experiences and through minimal points of contact – they just have to swipe their band. In addition, all of the information is aggregated and placed into databases used by Disney to monitor customer behaviours to understand preferences, experiences,

and opportunities for personalization allowing, them to tweak their service offerings to more accurately reflect consumer demand. Disney has moved from a passive entertainment approach to an interactive one that keeps guests constantly entertained and enables Disney design personalized services for customers. The data gathered through their MyMagic+ database will be used to create wait areas that can increase guest purchases and reduce the frustration caused by the inevitable lineup-related gridlock.<sup>54</sup>

Disney's expertise in achieving magical customer experiences may be an important opportunity for learning for health systems. Consider the use of the "Disney band" concept in hospital settings. Hospital bracelets enabled with "smart" sensors or RFID tags may enable hospitals or health facilities to identify a person's routines or preferences (such as activity patterns or hygiene) so that care processes could be more easily personalized to meet an individual's needs. Just like Disney uses the band to identify and track customer behaviour in theme parks, hospitals or clinics could track patient activity during waiting periods. This could allow the hospital to design more preferable waiting areas that offer additional services which could be revenue generators for the organization. Given that hospitals are often not considered secure environments to store valuables, linking a band to a credit card could allow mobile patients to purchase books in the gift shop or a coffee in the hospital cafeteria and therefore not have to worry about having cash stored in their room. General patient information could be contained on the band which could be swiped upon entering the facility, reducing the requirement to repeat information to each individual provider along the care chain. Organizations could also use this tracking data to better understand waiting routines and patterns to optimize appointment systems to better utilize health services and reduce wait times. Use of advanced information technologies could also be used to offer people the opportunity to book or cancel appointments online, receive notices of delays, cancellations, or changes in appointment times digitally, or access diagnostic tests remotely. And while a theme park may seem very far away from the experience of a hospital stay, patients already routinely receive a hospital band upon entering the facility. It is a small technology step to enable it to allow personalization.

### **Organization Example: Amazon recommendation system**

Many companies in the online shopping industry including powerhouse organizations like Amazon have also focused on personalizing consumer experiences.<sup>55</sup> Amazon gathers information from customers to provide personalized services; using a customer's previous purchases or browsing histories, Amazon generates unique promotions that match individual customer preferences. Personalization implemented by Amazon includes greetings by name, personalized recommendations, bestseller lists and personal notification services, as well as purchase pattern filtering. Amazon believes that customization and creating the perception of a one-on-one relationship with the consumer is essential to their value proposition, and the company continues to invest in ways that improve their personalization services.<sup>56</sup> Adding to the personalized shopping experience is the one-click technology used to save user payment information, reducing customer checkout time.

Personalization based on culture is a strategy used to align products and services with the cultural background of customers, which has been a powerful tool in industry to increase user satisfaction and an organization's revenue and market share.<sup>57</sup> Industries who expend considerable effort to successfully market a product or service, without recognizing local differences in cultural preferences, values and practices, would limit the success of gaining worldwide market share. Organizations understand and improve the quality of their

service in new markets simply by paying attention to the cultural values, expectations and experiences of the consumers they strive to attract to their products or services.

### **Organization Example: Tesco personalization based on culture**

An example of personalization based on culture is Tesco, a British multinational grocery and general merchandise retailer who successfully launched stores in South Korea, accounting for eight percent of Tesco's revenues<sup>152</sup>. Tesco was able to succeed in the South Korean market by tailoring their services to the cultural needs of the Korean population, and engaging their employees in a culturally sensitive manner by matching labour scheduling skills and core company values. Tesco adheres to Korean cultural standards, creating a workplace that is enthusiastic and team oriented; this is demonstrated in their worker social clubs, awards for service, and employee incentive systems. Healthcare systems serve populations which often represent highly diverse cultures, particularly in countries such as Canada, France, and the United Kingdom. Personalizing health systems using culture is an opportunity for health systems to achieve value for populations they serve. For example, considering ways employees can be engaged to align cultural values with specialize health services is a strategy that has been very successful in industry, however, has had little uptake in health systems. There are ways to tailor meals in hospitals and long-term care facilities to recognize cultural preferences and traditions, and personalize care experiences by providing choices in service delivery to respect cultural values.

### **Lesson Two: Use segmentation to achieve a "one size fits one" strategy.**

Segmentation is a strategy that acknowledges and understands that "one size does not fit all"; consumers vary widely in terms of their preferences, what is meaningful, what choices they will make and how they want to access services. Segmentation is a tool that industry uses to categorize their consumer population into groups that define the group's preferences, value, needs, or even demographic. For example, the sun-care industry segments their consumers by age, by activity preference, and specialized skin care needs. The industry then creates the products that best fit with each of the consumer segments, such as sun protection for skiers versus sunbathers, products for infants and children vs. adults, and specialized skin care products for people with tattoos.<sup>58</sup> By segmenting consumers by preference or demographic information, companies are able to drive sales by personalizing products to meet the specialized needs of each consumer segment.

A variety of industry sectors use segmentation to meet consumer demand for individuality which reflects what matters most to people, the inherent drive for self-determination, self-direction, independence and self-responsibility. As we move from a collective to an individual society, people seek products and services that reflect their individuality.<sup>59</sup> The search for individuality has resulted in consumers beginning to demand products that are tailored to meet their individual needs, which is clearly evident in the trends to use mobile technologies (ex. apps) to self-manage health and wellness. Typically, health systems tend to use standardized approaches to programs or services based on best evidence, and services are designed to achieve specific health or disease outcomes rather than meeting personalized approaches to care tailored to fit with the needs and values of the population. The goal of individuality is complemented by self-other comparison which has created a need for individuals to be different than others, and a wish to be judged as an individual rather than simply "fitting in". Individuality, as defined by industry, may be a concept that healthcare systems need to consider in order to transform from a knowledge intensive industry, which aspires to provide standardized care based on best evidence rather than individualized approaches to care based on

individuality and value. Personalization of customer experience using segmentation will be explored as a strategy for understanding the value and how other sectors have segmented populations based on common values. For health systems, segmentation may offer important opportunities to design and organize services to meet the personalized needs of specific segments of the population they serve to deliver value. The complexity of health systems is significant, unlike other sectors such as retail banking, travel, grocery, or retail. However, segmentation tools focused on understanding value associated with experiences in health systems may offer an important strategy for health systems to achieve value.

### **Industry Example: Insurance industry segmentation using health status and lifestyle**

In the insurance industry, "gerontographics" is a strategy used to segment the population based on the aging consumer's needs and life circumstances in order to develop specific insurance practices based on personal preferences. Gerontographics segments the senior population by physiological, psychological, and social characteristics. Consumers over the age of 55 are divided into four groups: "healthy indulgers"; "healthy hermits"; "ailing outgoers"; and, "frail recluses". These typologies segment seniors based on their health (healthy or ailing) and based on their need for socialization (i.e. hermits, recluses, indulgers) to provide insights into the health and lifestyle preferences of seniors. These segmentation groups are useful in a variety of industries for developing products and services based on the desires of each group. For example, healthy hermits and frail recluses would be attracted to products that enable them to remain independent at home, while healthy indulgers and ailing outgoers may want programs and services that engage them socially outside the home. There are other subtle differences between segments; healthy hermits express less interest over control, while ailing outgoers express an increased value placed on home and companion services. Gerontographics has demonstrated that the most important factors for the aging population is the freedom of the individual to choose their place and type of health and personal care.<sup>60</sup>

Consider the opportunity for healthcare systems to segment the population they serve based on the age and health status of seniors in the population. Essentially, health systems could mimic insurance segmentation, designing service delivery models so that population sectors can have a choice and healthcare services can be personalized to effectively meet the needs of each sub-group such as the "healthy hermit", or the "ailing outgoers". The most valuable lesson health systems can learn from insurance may be to recognize that "one size will never fit all", and a more personalized approach can be successfully achieved by recognizing that groups within the population vary widely and health services need to be structured using a variety of approaches in order to meet the unique needs and values of all segments within a population.

### **Industry Example: Retail banking segmentation based on risk taking, experience and expectation**

In the banking industry, consumers are able to access services online, 24 hours a day, tailored to individual preferences.<sup>61</sup> However, it goes beyond just delivery channels; retail banking consumers are also able to develop customized investment packages through the selection of investments based on their risk tolerance, time horizon and investment goals.<sup>62</sup> In essence, these customers are each creating a personalized investment fund. However, unlike the insurance industry, segmentation methods based on demographic information have failed to produce attractive results.<sup>63</sup> Retail banking has learned that segmentation models fail unless personality differences related to behaviour are considered as part of segmentation decisions.

In retail banking, psychographic models have been used to identify investor motivations, resulting in segmentation based on risk tolerance. In these segmentation models, consumer stratification is developed based on risk the individual is willing to take; this has created "risk-taking" classifications such as conservative, moderate, and aggressive.<sup>64</sup> Other segmentation methods have looked at the investor experience as a means for segmentation including classifications such as "financially confused", "apathetic minimalist", "cautious investor", and "capital accumulator".<sup>65</sup> Investor expectation is another segmentation approach resulting in classifications of "idealist", "pragmatist", "framer", "integrator", "reflector", and "realist." A combination of these modes has been used in banking to segment consumers into broad groups based on investor types. These types include "cautious", "confident", "optimist", "careful", "realist", "individualist", "integrator", and "well-balanced." Segmentation along these metrics allows for personalized services that work with the person's strengths and weaknesses, but still allow for economies of scale in the development of marketing products or mutual funds based on these typologies. Not unlike the insurance sector, banking has identified the importance of recognizing the individual personality traits relative to risk tolerance matter in terms of the value consumers aspire to achieve when accessing banking services.

Segmentation based on risk may offer important insights for health systems. Banking focuses on the individual's comfort level for taking on the risk of losing money when investing. Risk in healthcare might be viewed in terms of risk of becoming ill, particularly the risk of becoming chronically ill. Health systems are increasingly challenged by growing rates of chronic illness related to lifestyle behaviours such as diet and exercise. However, prevention programs focused on healthy eating and exercise have yielded little evidence that these lifestyle trends are declining despite the risk of chronic illness associated with lifestyle. To date, health systems (i.e. public health programs in particular) have tended to use a "one size fits all" approach to educating populations about health behaviours such as diet, exercise, smoking, and the use of alcohol. The retail banking sector may offer important lessons for health systems to learn about segmenting populations based on personality types which may achieve greater impact if prevention programs were personalized to fit with the unique values of population segments. The "healthy hypochondriac" may engage in formalized prevention education programs more readily or differently than others who are more risk tolerant, and may value more convenient digital prevention programs that fit their lifestyle. Health systems may also consider designing preventive programs personalized to population segments based on actual risk of chronic illness. As an example, many health systems are currently struggling with high rates of mental health challenges children and youth. These systems may learn a valuable lesson from retail banking and use segmentation strategies to identify the needs, values and preferences of sub-groups of children and youth at risk of mental health challenges in order to design more effective prevention programs that are personalized to the unique needs and values of each sub-sector of the child and youth population.

Given the increasing demand for health services which is raising health expenditures almost exponentially, the use of segmentation may also provide a solution to help manage health costs. There is an economic incentive to assess individual risk of chronic health conditions, as chronic health conditions cost companies 10.7 percent of their total labor costs.<sup>66</sup> To assess risk, companies appraise employees' physical and mental health, healthy behaviours, work environment, basic access, and life evaluation.<sup>67</sup> These metrics are measured as they impact presenteeism and job performance. After these areas are measured, employers then decide on the proper intervention required. Evidence has demonstrated that workplace intervention may improve mental health, disability and employee turnover.<sup>68</sup> By measuring quality of life before taking action, interventions will be more effective as preventative care programs offered only to

those at risk of developing chronic conditions may very well increase the benefit-to-cost ratio of healthcare systems in a number of countries.

Willingness to pay is an interesting concept for all health systems to consider. Whether it is considered relative to voter preference in publicly funded health systems, or more consumer based systems such as the United States and Switzerland, willingness to pay is a concept that has remained largely unexplored relative to the personalization of healthcare. The concept of willingness to pay recognizes that income levels within the population vary widely. Industry – across the board – has recognized this fact by creating a range of products for various income levels by taking advantage of each population segment's willingness to pay to maximize revenue. This has been done by creating differentiated products for which consumers are willing to pay a premium price over the low cost alternative. This can include elements such as quality, exclusivity, safety, brand, and service delivery.

### **Industry Examples: Automotive and retail segmentation based on willingness to pay**

The automotive industry demonstrates segmentation based on willingness to pay. Companies such as General Motors have created a number of brands to appeal to different income levels. Car market segments include basic, small, lower-medium, upper-medium, executive, luxury, sports, minivan, and SUV.<sup>69</sup> Different offerings within brands allow customers to evaluate the specific product based on whether it is best suited to their needs,<sup>70</sup> which allows the company to fulfill an entire population's quality and price demands by offering a variety of products or services. Brand extension can be used to either step up or step down in terms of the types of customers targeted. For example, Purina ONE, a pet food supplier now offers luxury cat and dog food with a price premium as well as its lower priced, mid-level Purina brand.

Willingness to pay is a strategy that has a varying degree of utility in health systems. Funding models for health systems determine the level of choice consumers have in deciding which health services they will access based on, directly or indirectly (depending on the country), a person's "willingness to pay". Health systems have, and may continue to design strategies to personalize their services using "luxury" features that segments of the population value and choose to access. Currently, one could argue that hospitals offer private rooms at a premium price to the consumer. Health systems may benefit by considering ways to segment additional "luxury" services that may be valued by consumers in order to strengthen experience and enhance personalization for populations. For examples, the availability of digital platforms or "apps" could be offered for a premium price to consumers, providing targeted segments of the population (i.e. the "healthy hermit") with health information or services that are of specific interest to them. This may offer health systems or private-sector companies additional opportunities to personalize services external to publicly funded models of healthcare. Health systems may benefit from taking a broader perspective and considering how "willingness to pay" offers a strategy to more effectively personalize health systems to fit with the values across income sectors of the population they serve.

Segmenting the consumer base may be done in a variety of different ways. However, all methods have in common the primary goal of grouping the population into segments based on key features that could be used to personalize health services to achieve value. Segmentation of populations based on experience, value of time, knowledge of health, and expectations offer ways that health systems could personalize care and tailor approaches to achieve value.

### **Lesson Three: Use customization as a strategy for personalization.**

Customization is another strategy for achieving personalization. It differs from segmentation in that some of the responsibility of personalization lies with the consumer rather than the supplier. Rather than guessing or studying customer desires, customization involves strategies that enable the consumer to instruct the company or organization (i.e. health system) on how best to engage them to achieve their goals. Customization eliminates possible misinterpretation of what consumers want and value, and reduces the costs related to delivering services or products that are not used by the consumer or are not valued by them. The most important feature of customization may be the ability of the health system to actively engage consumers in tailoring services to achieve value.

Traditionally, the manufacturing industry has focused on maximized efficiency through standardization, but has more recently experienced a shift in production strategies with customers now demanding greater input into the design and quality of products and services without paying the full cost currently associated with customization.<sup>71</sup> Manufacturers are moving towards mass customization, a system that combines the low unit costs of mass production processes with the flexibility of individual customization,<sup>72</sup> as a way to offer personalized products at a lower cost, attracting a greater diversity of customers. In the healthcare industry, there could be an opportunity to better understand "mass customization" due to the increasing volume of patients as a result of factors including increased life expectancy and growing prevalence of chronic illness.<sup>73</sup> This growing demand for care puts pressure on health systems and has been managed by attempting to increase efficiencies in time or quality, using techniques such as Lean, a concept that originated from the automotive industry (Toyota Inc.). While processes designed to achieve efficiency in hospital-based services may decrease time and increase productivity, these approaches will do little to decrease volume due to growing demands over time, particularly for aging populations and the growing population sector with chronic illness. Customization strategies that focus on prevention and self-management of health and wellness may more effectively strengthen quality of care through mass customization, while at the same time reducing demands for expensive hospital care.

In healthcare, two technological advances are making customization possible: personalized medicine, whereby therapies are customized to the genetic make-up of individuals; and advances in information technologies, which enable direct communication between populations and their health systems.<sup>163</sup> These advances offer health systems opportunities to engage consumers directly to "customize" health services and approaches to care, while at the same time allowing innovative communication strategies to engage consumers more directly in achieving value relative to health, wellness, and quality of life. Examples of the use of mass customization in other sectors provide further insights into how health systems may engage this strategy to achieve personalization of health systems.

#### **Industry Example: Mass customization in the apparel industry**

Though individual customers are unique, the apparel industry is increasingly using mass customization strategies to respond to consumer trends and customer input in clothing design.<sup>74</sup> Companies such as Nike and Kate Spade allow individuals to take a standard product such as shoes or handbags and customize them based on limited selection of designs, colours, and materials. New technologies including fully-body scanning, computerized routing and made-to-measure pattern development are achieving personalized fit which has been shown to be the most important issue for consumers<sup>167</sup>. The comparator in

health systems is the emerging technology that creates "made to measure" therapies based on genomic technologies to offer a personalized fit with consumers. Although this technology is emerging rapidly, genomic therapies have not been mobilized across health systems to date largely due to their excessive cost.

### **Industry Example: Mass customization in the automotive industry**

Currently, the automotive industry uses four ways to achieve mass customization: product design; process design; information system; and, process management. The auto industry uses a virtual "build to order" (VBTO) approach to engage consumers directly in the product design. Using a standard vehicle design, consumers can select different features such as automatic transmission, type of interior, heated seats and steering wheels, GPS systems, and sound systems. To make it easy on the consumer, car companies offer "product packages" which offer, at a discounted price, a grouping of the most popular options. This type of consumer choice could be adopted by health systems to allow for customization within largely standardized health systems system. Consider a health region that serves a wide range of communities, some of which are rural and remote, others which are urban, and populations within each community that vary in terms of age and healthcare needs. Customization to create "product packages" could engage each of the diverse type of communities to design how community-based care and services are offered to elderly citizens in each community. Home visiting in rural and remote communities would very likely need to look different from services in urban communities which have close proximity to health professionals and health organizations. Customization of health services could be designed with the input of individuals they are designed to serve. This way they would be far more likely to achieve seamless service models to deliver value to each community.

Health systems have much to learn from industry in terms of how to personalize products and services to achieve value for "customers". Personalization strategies that identify and then tailor services to the unique needs and expectations of consumers offer health systems a way to move beyond the "one size fits all" approach to healthcare to begin to transform the system to a "one size fits one" philosophy. To accomplish this, healthcare needs to develop tools, services, programs, and organizational approaches

that make the individual feel like an individual, rather than just an anonymous number in a system. Industry has demonstrated countless successful approaches and examples of how to personalize services for entire populations to drive market share and revenues. Personalization of health systems can achieve the same value proposition for populations they serve, simply by learning by example of other industry sectors.

## Section 4: What Does a Personalized Health System Look Like?

Health systems are struggling to achieve accessible, efficient, quality healthcare services that are cost effective, based on the best evidence available and delivered by specialized clinical teams who function autonomously in distinct health organizations. The sustainability of this provider-focused, supplier-driven approach has resulted in a "transactional" health system where care is divided into discreet and siloed units that do not hold any single provider or organization accountable for health outcomes.<sup>75</sup> This type of health system, the dominant paradigm in most developed nations, has resulted in a high volume of care with limited accountability for outcomes that align with priorities and value of populations.

However, the rapid changes in medical services and technologies paired with the voracious consumer-led demand for individual and system level health information are eroding the traditional supplier-driven health system model. It is no longer about what services you deliver, but what value these services achieve for health consumers and populations. It is no longer "one size fits all", but rather "what size fits me?" The future of healthcare is the personalization of health systems in a way that achieves value for the population. This can be achieved by customizing services with embedded accountabilities for achieving targeted outcomes that matter to people,<sup>76</sup> measuring what worked and what did not work, and making the necessary changes, and coordinating care across the entire continuum so that every provider has a stake in achieving the personalized goals and aspirations of individuals, families and communities to whom they provide care. In a personalized health system, every care provider, every health team and every organization has "skin in the game"; resources are allocated to engage and incentivize multiple providers and organizations to work together to deliver value to the populations they serve.

Personalization of healthcare implies a change in mindset from primarily diagnosing and treating illness to determining what health solutions will enable and empower people to achieve their health goals in a manner that fits with their lifestyles and cultures. It requires healthcare practitioners to recognize that engagement with patients means much more than their compliance;<sup>77</sup> in the patient-engagement paradigm, non-compliance means a patient's treatment plan was not right for the patient. In a personalized system, decisions reflect the values of the person, community, or population; the power is localized at the bottom and flows up, rather than the "top down" hierarchy of traditional health systems. The quality of health outcomes are measured in terms of accuracy and relevance to population values, rather than safety/errors related to adverse events. At its core, the structure of personalized systems shift from an authoritarian, command and conquer, decision-making structure to a collaborative model that empowers individuals to design and manage the care that is needed to meet their personal health, wellness and quality of life goals and expectations. Key features of a personalized health system are presented in Table 2.

**Table 2: Key Features of Current Health System versus Personalized Health System**

CURRENT HEALTH SYSTEM STRUCTURE AND APPROACH	PERSONALIZED HEALTH SYSTEM STRUCTURE AND APPROACH
<p><b>Equity and Access:</b> Equity and access are based on what is available in terms of health services or programs. Efforts are directed to ensure access to the same service or program is available to everyone in a population, with minimal wait times. People seek care through formalized health services provided by hospitals, clinics, health teams, or individual practitioner office visits.</p>	<p><b>Equity and Access:</b> Equity and access are based on what is meaningful relative to quality of life and wellness within segments of society. Equity of service delivery is considered relative to outcomes such as whether health, wellness and quality of life are being achieved or supported. The focus is achieving population health outcomes that fit with values of the population. Access to specific services may vary with the unique needs and profile of sub-sectors within the population; the focus is on the outcome of achieving value. Access is defined by whether populations are able to access the services they want, and are able to choose the method or mode of service delivery that best suits their needs and expectations (i.e. online access, in person access).</p>
<p><b>Mandate:</b> Deliver services that offer care for illness, disease or injury, when care is needed and where care is needed. There is a strong focus on cure, and disease or illness management.</p>	<p><b>Mandate:</b> Personalized health systems are informed by population values, whereby individuals, community, population collaborate with health system leaders to design services to achieve value by supporting quality of life, health and wellness. Care is personalized to the person/community population, based on priority health outcomes.</p>
<p><b>Decision-making:</b> Treatment decisions are made on the basis of clinical judgment and best evidence (clinical trial results), primarily by health professionals. Health professionals are viewed as the experts who assess, diagnose, make decisions about treatment protocols, inform the patient of the protocol, and follow-up on whether the person followed the prescribed therapy. Priorities for decisions focus on patient safety, clinical guidelines based on evidence, and achieving outcomes aligned with best evidence. Health professionals are the "experts" and patients are the recipients of care.</p>	<p><b>Decision-making:</b> Decisions are made by the individual based on their personal health and wellness goals. Providers collaborate with the individual to ensure they have all the information needed to make informed decisions. Providers work with people to establish the goals and outcomes they want to achieve. Health services are personalized to fit with a person's values, needs and expectations. People are the "experts" in the system, providers are the "coaches" who assist and support people to manage their health and wellness and support them to make informed decisions across the care continuum.</p>

<p><b>Health Provider Dialogue:</b> Focused on the disease, the illness, or healthcare procedure. The dialogue focuses on a series of questions to complete an assessment and diagnose the disease or illness. The dialogue is directed by the physician provider, and the person answers questions and receives information about how to follow the treatment. The dialogue does not focus on the person, but rather the disease or illness.</p>	<p><b>Health Provider Dialogue:</b> Focused on the person, the goals and objectives for which they are striving, their unique and special needs and expectations. The focus of the dialogue is driven by the individual, what they want to achieve, what matters to them, and how the provider can help the person achieve what is most important. The provider role is to identify all the options and then support the person to choose the option that best suits their needs and expectations. The dialogue is person focused, not disease or illness focused.</p>
<p><b>Role of Providers:</b> Providers or teams diagnose, prescribe, and implement care based on currently accepted standardized protocols. Presently, providers make the decisions and patients decide to comply or not, often not returning to the provider or waiting until condition worsens to require hospitalization</p>	<p><b>Role of Providers:</b> Providers work collaboratively with individuals or communities to inform them of the range of options, risks and opportunities, and assist the person/community in choosing the option that best fits with their goals for quality of life and wellness. The person makes decisions on treatment or therapies that best fit with their personal health and wellness goals. The provider is the "coach and mentor" to support the person's decision.</p>
<p><b>Healthcare Services Structure:</b> There is a downstream focus on managing illness, disease, limiting "damage control" to improve the outcomes of the illness.</p> <p>An example would be fall prevention for seniors in long-term care facilities to ensure safety.</p>	<p><b>Healthcare Services Structure:</b> There is an upstream focus on supporting and sustaining wellness and quality of life to prevent illness or address health challenges.</p> <p>An example would be exercise and wellness services for seniors to support independent living.</p>
<p><b>System Outcomes:</b> Health system tracks quality, and performance relative to safety (error, adverse event), cost, quality of outcomes, and patterns of utilization.</p>	<p><b>System Outcomes:</b> Health system segments population on risk and engages preventive approaches that are designed in collaboration with the population segment to ensure strategies that are meaningful and achieve measurable value.</p>
<p><b>Outcome Measures:</b> Outcome measures include a focus on clinical outcomes associated with clinical practice guidelines best evidence, quality, safety, readmissions to hospital, morbidity, mortality, error, and the performance of clinical processes such as efficiency, wait times and accuracy.</p>	<p><b>Outcome Measures:</b> Measures include priority health outcomes for the population which are linked to health, wellness, and quality of life. Examples of priority outcomes could include lifestyle behaviours (i.e. vascular health), prevention outcomes measures (i.e. immunization rates), mental health outcomes (i.e. employment, social support) and end of life goals (i.e. remain independent, die at home).</p>

<p><b>Infrastructure:</b> Hospital dominant. Services are transactional, disease focused, organized by specialization and most often delivered and managed by specialized healthcare teams. Specialist teams lead service delivery, and there is limited or no interaction between specialist teams, hospitals, rehabilitative care, community care, or primary care health providers.</p>	<p><b>Infrastructure:</b> Community dominant. Services and programs are focused on mobilizing and building capacity in communities to support population health. Community teams lead service delivery, coordinate and integrate services, offer choices to people on how to access services and how they want to communicate, and work with providers to achieve health and wellness. Hospital care is restricted to acute care services only and is coordinated with community services to achieve health goals across the continuum of care.</p>
<p><b>Access to Information:</b> Information is managed and accessible only to health providers and health system leaders. Patients may request information and with permission (and payment in most instances) and receive information vetted by the provider and health system. There are few opportunities for information to flow freely between providers and patients, or between providers across organizational boundaries such as hospitals to community to primary care.</p>	<p><b>Access to Information:</b> Information is open and accessible through a variety of mechanisms (i.e. online), as it is managed and organized around the person. Community information is widely disseminated and communicated effectively to inform decisions to achieve population values as the democratization of information principle underlies health information systems. Information empowers people and communities, providing a real-time support for decisions that achieve the values of individuals or populations. As the information is attached to the person rather than the provider, it shifts the balance of power from a provider dominant dialogue, to a more collaborative and coordinated dialogue between people and a range of health providers and organizations. Algorithmic tools are used to inform and support self-management, designed specifically for recipient with built in tools for people to set goals that are consistent with their values.</p>
<p><b>Funding Model:</b> The payment model is based on health transactions - "fee for service" - which reimburses providers for providing a particular service (i.e., consultation, procedure, diagnostic assessment). Funding models for organizations focus primarily on the volumes of services provided to a population or community.</p>	<p><b>Funding Model:</b> Reimbursement is attached to the achievement of priority health outcomes for defined segments of the population aligned with their goals and values. Health teams are incented to achieve outcomes and the processes they use to achieve outcomes are determined collaboratively with people and their families. Collaboration across the continuum of care is incentivized, as payment is linked to health outcomes that all provider organizations teams have a role in achieving. Payment is tied to achieving measurable targets, bonuses are provided to exceed targets. Targets are established jointly by the health system and population it is serving, anchored in values such as health, wellness and quality of life.</p>

Reaping the benefits of personalized health systems requires incentives that target society, healthcare providers and individuals to achieve outcomes that achieve value. For this type of shift in healthcare models to be successful, the reimbursement system for healthcare practitioners will need to be adjusted so that providers are compensated for a broader spectrum of elements. Such a system will no longer be about how many patients can be seen in a single day, but rather whether the value based goals agreed upon by the provider and the patient have been achieved. This shift from the transactional to the personal will require clinicians to be educated and socialized to actively engage people differently, and positively and proactively communicate with people in order to unpackage what patients are truly seeking.<sup>78</sup> A study by Vanguard Communications found online complaints about physician bedside manner and customer service were four times more common than complaints about medical skills; thus, patient satisfaction may depend more on physician's personal skills and facilities' efficiency than a provider's technical knowledge.<sup>79</sup> As such, new personalized health systems may involve reimbursements being linked to patient experience as an outcome upon which payment is contingent.

A key enabler for this system transformation will be a shift in the business model of healthcare from volume-based funding approaches (i.e. fee for service) to value based accountable care models which are beginning to emerge in a number of countries.<sup>80</sup> Accountable care funding models reimburse health systems to achieve priority population health outcomes,<sup>81</sup> personalized to the unique needs and values of defined populations. Health teams across organizations are mandated to work together to create collaborative and integrated models of care that focus on target health outcomes for the population. For this type of a system to work, societies will need to engage in challenging decisions to determine how health systems can best achieve priority health outcomes for populations, based on values, and how people, communities, and populations need to be partners with providers in assuming responsibility for achieving outcomes. Accountable care health systems offer an important framework for health systems to work towards to achieve personalization. Figure 1 illustrates the key principles of accountable care for populations.

**Figure 1: Accountable Care Model for a Population**

<p>Delivering accountable care for a population involves five key components:</p> <ol style="list-style-type: none"><li>1. A specified <i>population</i> for which providers are jointly accountable.</li><li>2. Target <i>outcomes</i> for the population outcomes that matter to individuals.</li><li>3. <i>Metrics and learning</i>, to monitor performance on outcomes and to learn from variation.</li><li>4. <i>Payments and incentives</i> aligned with the target outcomes.</li><li>5. <i>Co-ordinated delivery</i>, across a range of providers, of the care necessary for achieving the desired outcomes.</li></ol> <p><a href="http://wish-qatar.org/reports/2013-reports">http://wish-qatar.org/reports/2013-reports</a></p>
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Creating a personalized health system requires a change in mindset from primarily diagnosing and treating illness to determining what health solutions will enable and empower people to achieve their personal health goals, in a manner that is a strong fit with their lifestyles and cultures. It requires healthcare practitioners to recognize that engagement with patients means much more than their compliance. This model of healthcare is slowly emerging in a number of countries, and while evidence of achieving priority outcomes has not yet been established, early indicators are promising. The accountable care model shows potential and demonstrates a very important shift in health systems from the current "one size fits all" approach towards a system level personalization focused on priority population health outcomes and supported by incentivized funding models that reimburse for achieving outcomes, rather than just delivering services.

# Section 5: Ten Steps to Achieve the Personalization of Health Systems

Health systems around the world have achieved somewhat limited progress in personalizing health services to achieve value for the populations they serve. How can health systems personalize their structures, services, and care delivery models to achieve a personalized system that achieves value for the populations they serve? We offer 10 steps to achieve a personalized health system, which can be tailored to the unique cultural and population values.

## **Step One: Reframe the conversation from "What is the matter" to "What matters to you".**

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People judge the experience in healthcare by the way they are treated as a person, not by the way their disease is treated or by a provider's assessment of their "clinical outcome".<sup>83</sup> In our current healthcare system, conversations focus on the illness or injury, not on the person. This goes as far as dehumanizing individuals and identifying them by their disease. We describe people as a "cancer patient" or a "cancer survivor", "a COPD patient", "she is autistic", "he is bipolar". They become defined by their illness, not by who they are as a person. This has become institutionalized in our health systems; when entering an admitting department of a hospital a person is usually greeted and asked, "What is your name? Who are you here to see?" and then informed, "Just sit over there until your name is called". When entering an emergency department, the dialogue begins with "What brings you here today?" or "What seems to be the problem?" A personalized health system begins with the person, not the illness or treatment or disease.<sup>84</sup> Making a personal connection with the individual – as an individual – sets the appropriate tone from the beginning of the interaction at a level and context that focuses the dialogue on the person, not on their disease or illness.

The first step to personalization is documenting and framing the conversation around what matters to people as individuals, identifying personal health and wellness goals, which shifts the entire dialogue to focus on the person, not their disease or illness. In every subsequent conversation or transaction, the health and wellness goals are the focus of the conversation and the treatment plan is specifically designed in collaboration with the individual to achieve personal goals and outcomes. While it sounds simple, considering people to be individuals rather than elements of a system, and determining what matters to them rather than what is the matter, reframes the conversation and the experience in the healthcare system to focus on the person rather than the disease, disability, or injury and the treatment protocols they are undergoing. It is a critical first step to create personalized health systems.

## **Step Two: Redefine success in terms of health and wellness outcomes that are valued by a population.**

Every health system in the world measures health system performance outcomes such as quality, safety, access, and satisfaction; these indicators have been the dominant focus of health system quality and performance for decades. These measures focus on the transactions and the services they provide related to diagnosing, treating, managing or curing disease or injury. Success of most health systems is defined as achieving the best possible quality outcomes for the patients the system serves. Yet, these clinical outcomes are of limited value from the perspective of the individual person, family, or community. What people really value is their wellness and quality of life.<sup>85</sup> In order to achieve a personalized health system, we need to define success by mapping health and wellness outcomes/goals onto the important work of clinical quality and performance outcomes throughout the health system.

As an example of the disconnect between clinical and system indicators, and personal wellness goals, consider the elderly man who goes to his primary care physician about having to get up at night several times to go to the bathroom causing him frustration and exhaustion day after day. The man is referred to a specialist and receives a diagnosis of early bladder cancer. The treatment plan is to eradicate the cancerous cells in the bladder. He undergoes treatment which is deemed highly successful by all measures of quality and clinical outcomes in the healthcare system; the cells are gone and there is a low risk of their return. When you ask the patient if he achieved his health goals, he passionately states, "No, it was a big waste of time and I am not going back!" When asked why he feels it was a waste of time, he states, "Because I still have to get up at night 4 or 5 times and that was why I went to see the doctor in the first place". The clinical outcomes for this man were highly successful from the health systems viewpoint; yet achieving his personal health goals of getting a good sleep at night without waking up were a miserable failure and he now refuses to continue the recommended follow up prescribed by the specialist. A personalized health system would build a treatment plan for this man that includes a strategy or support for managing his nightly urinary issue, which is eroding his quality of life as he is chronically feeling fatigued and frustrated.

Another example of the current disconnect can be seen at the community level. Consider a community which has growing concerns about the number of young people and their families experiencing, what they perceive to be, higher than normal rates of mental health challenges. The health system responds by examining the community's access to mental health services and implements a strategy for community members to access treatment for mental health in a timely manner. The community is grateful for the improved access to care. However, they are highly dissatisfied that their community has so many young people experiencing mental health challenges with no strategy in place to figure out why there is a high prevalence, and no acknowledgement of the need to reduce the prevalence through proactive prevention programs.

Step Two in personalizing a health system requires building the customized outcomes identified in Step One into measures of health system achievement that reflect what people view as success - the health and wellness goals of the person, family, and community. Personalizing success means that every region and each sector of the population will have different measures or outcomes that reflect the uniqueness of the community or population. This step does not suggest ignoring or moving away from clinical outcomes of quality, safety and performance based on best evidence; rather, it suggests building a personalized wellness focus into existing measures of success in a way that incorporates the individual or community's unique objectives.

### **Step Three: Put people in charge - shift the decision-making process from the "Provider as Expert" to the "Person as Expert".**

In current healthcare systems, the health professional or health team assesses the patient and makes decisions on the most optimal treatment plan. The patient consents to proceeding with the care strategy and then implementation of the care strategy begins. The reality of most health systems is that individual patients are assessed and treatment protocols are followed based on best available evidence to achieve specific clinical outcomes. Decisions are by and large determined by the health provider (or team), personal health information is managed by the health system organization or practitioner, and patients are primarily in the role of "recipient" of care and are expected to follow the protocol that is prescribed. Even when patients question care decisions, there is a rather uncomfortable dynamic as the top-down power dynamic is being challenged. The power imbalance in the patient-provider relationship is described by Macleod and Kushner:

Any economist who persists in believing that healthcare is a market product just like any other has not spent any time as a patient. You give up your body and power to an institution and a team of strangers. They have all of the technical knowledge, you are on your back and are scared. The last thing you are is a shopper and bargaining agent. There is nothing new in what we experienced – it is the reality of being a patient in a system that struggles to get things right. Perfection is unattainable, but we will never approach perfection unless we commit to settling for nothing less.<sup>86</sup>

In the current system, the power balance is clearly in favour of the health system, which determines resource allocation to support service delivery in the communities the system serves. By design, health professionals offer those services to individuals/communities within the constraints the system places upon them. Consider the example of an elderly woman with Alzheimer's disease who always told her family, "Don't ever put me in one of those places (Nursing home). I would rather die than be in a place like that". When the primary care physician meets with the family to discuss strategies for keeping the woman safe from wandering at night, he suggests "long-Term Care is really the best available option for your mother. It is a home-like environment and is a locked facility so that she will always be safe, and her safety is the most important priority for her". When the family identifies the woman's wishes, the physician defends his recommendation stating, "If it were me, I would have my parents in this facility in order for them to be well cared for". Inherent in this dialogue is the assumption that the physician "knows best"/ In this case, the priority goal from the physician's perspective was to ensure the woman's safety by putting her in a locked facility. The limitation of this system is that the provider as expert identifies the goals for the person or for a family; there is no discussion of all potential options to determine the best fit with the individual and family's needs.

Putting the person in charge, or, in the case of community organizations, putting the community in charge, means changing the power balance in the healthcare system from the dominant provider focus to a dominant person/community focus. A personalized system shifts this imbalance to one that supports individuals, families, or communities in making decisions about their own health, and designs care strategies or approaches that are tailor made to fit with the individual's personal values and health and wellness goals. Placing the individual in charge of decision-making allows for discussion to be framed around what the individual wants, and should help narrow the available treatment/or healthcare options to those that best suit the individual's wellness goals and aspirations for achieving quality of life. The role of the health provider shifts from being the decision-maker to being the facilitator of the decision-making process. Once an individual defines what success looks like with and for the health provider, the conversation moves to examining all possible treatment options against how well they achieve the health and wellness goals of the individual, family and community they live in.

Returning to our example of the women diagnosed with Alzheimer's disease, the conversation in a personalized health system would be very different. It would begin with the physician asking the woman, "What is the most important consideration for you when choosing where you want to live and what help you might need from time to time?" The physician would also ask the family "Can you describe your mom and what is most important to her?" On the basis of these conversations, and based on the woman's articulated goal of staying independent in her own home, the physician would proceed to identify options for care for the woman which could include staying in her own home with additional supports, moving to the home of a family member (if that was an option), or moving to a community setting that was as homelike as possible. Putting the person in charge in this case also require the support and active engagement of the person and their family to determine the most optimal plan for this individual. An open dialogue with the person and their family would begin with discussion about what is most important to the individual in terms of wellness

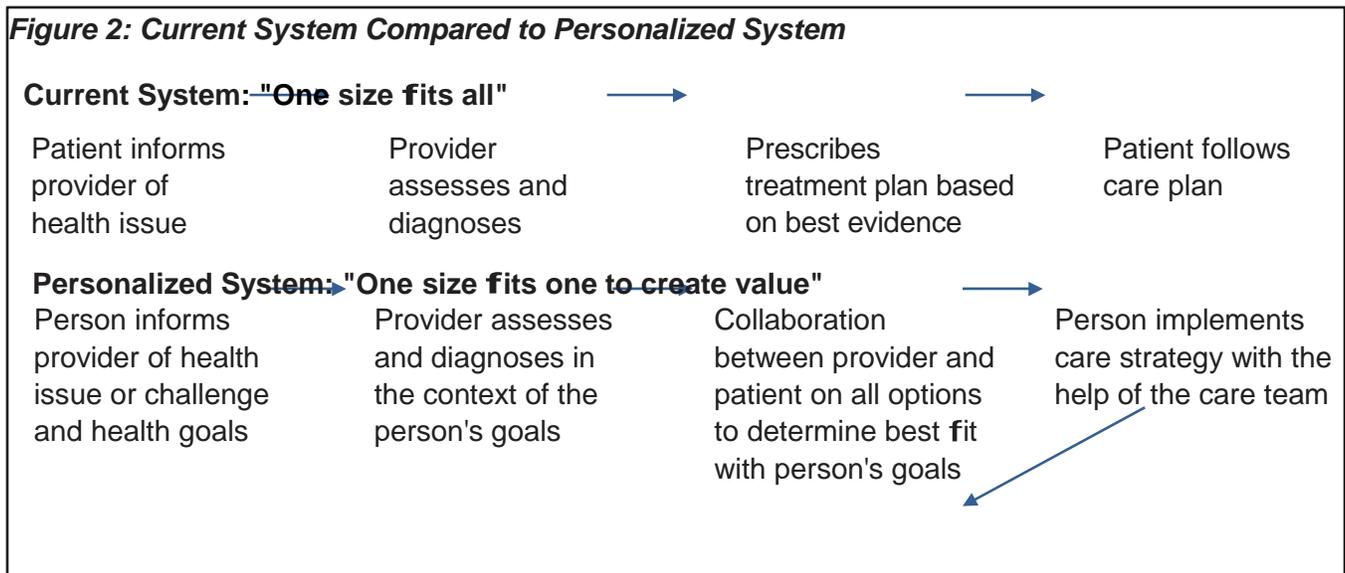
and quality of life. The individual who states, "Promise me that you will never put me into one of those nursing homes", is clear on her goal, positioning the decision-making discussion to focus on supporting the individual's wishes. The physician or healthcare provider would then be able to facilitate a discussion among the family members to determine the most optimal, realistic and achievable options for their loved one as the disease progresses. The discussion would examine how each option meets both the person's wishes and the family member's ability to care for their mother in the community.

Decision-making in a personalized system is always the role of the person, family, or community (in the case of community based models of care). The provider's role is to facilitate and support decisions as a collaborative partner, where the dialogue and decisions made reflect the person's aspirations for quality of life and wellness. In a personalized system, the focus on nurturing the individual based on their goals and values creates the conditions for the person to identify what success looks like, and then work with the health team to design the healthcare strategy that achieves that success.

**Step Four: Shift care processes from "One size fits all" to "One size fits one".**

Step Four requires health systems to turn the current person-health system interface "inside out", so that it is meaningful. Consider the example of the middle-aged man who is experiencing irregular heart rhythms and requires a pacemaker to restore heart health. He lives in a small rural community which has no access to specialist cardiology care within a 300 km. radius. Once the pacemaker is installed, best practice models for restoring cardiac arrhythmias include (evidence-based) follow-up care for monitoring the effectiveness of the pacemaker, educating the patient on heart health, consulting with the cardiologist on changes in the patient's condition, and following cardiac wellness protocols that re-build and strengthen heart health through exercise and lifestyle changes. In the traditional health model, to follow these best practice guidelines, our patient would have to travel regularly to access this type of care which would require a loss of time at work, expense and inconvenience. While the clinical goal of restoring heart health has been met with the pacemaker, the system has not adapted strategies to meet to the individual's personal circumstances and goals. In short, the person has to fit into the model of care, as the traditional care model is not tailored to fit with the personal needs, values, and health goals of the individual.

Step Four suggests that a personalized health system requires that the current "one size fits all" solution be flipped to a "one size fits one" approach. Figure 2 illustrates the difference in the two models.



Meaningful experience, supported by collaboration  
with health team to achieve person's wellness goals.

Step Four focuses on how care happens in personalized health systems to ensure that it is linked to a person's health and wellness goals. It is one thing to suggest that the conversation needs to be reframed to "what matters to the person"; it is quite another to implement the care, therapy, or protocol in a manner that is personalized to what individuals value. We recognize the fundamental shift this will require given that every health professional, in almost every developed health system today, has been educated and socialized to practice within guidelines based on "best evidence" or "best practice" frameworks, defined by clinical trials or research. Personalization of health systems will require embedding a personalized strategy into every service delivery model which requires practitioners to really understand what matters to their patients. We are not suggesting that current evidence based protocols or care processes are no longer appropriate; we believe that a shift to a personalized health system will require that current protocols/processes be implemented in a manner that is aligned with the person's goals, and values. To achieve this transformation, providers will require education programs to socialize them towards a collaborative partnership model, rather than a dominant decision-maker role.

A focus on "one size fits one" will also require health professionals to be educated as members of an interprofessional healthcare team, who collaborate with colleagues across the continuum of care, all collectively driving to achieve health and wellness goals of an individual or population. In a personalized health model, the territorial "scope of practice" debates of yesterday must shift so that health teams – who incorporate all elements of the care continuum – debate and dialogue on how best to work together with people in achieving their health and wellness goals. These interprofessional health teams must identify and respect the contribution and expertise of all team members, rather than following the prescriptive, hierarchical model of today that is focused on individual health situations or events related to disease or illness.

Step Four builds on shifting the dialogue towards the whole person, delivering the best practice protocol or care pathway in new and different way in collaboration with the patient and the entire care team. Returning to our pacemaker example, strategies such as Skype consultations with cardiologists after an individual's work hours enable a meaningful dialogue "in person", and use technology to overcome geographic distances. Other strategies could include creating online cardiac wellness programs that link people in rural communities to the same quality of cardiac wellness programs available within urban cardiology centers. Personalizing health systems means tailoring best practice protocols and programs of services to be accessible and achievable to all who need it, personalized in a way that achieves health and wellness goals within the unique circumstances in which they live.

### **Step Five: Stop competing and start collaborating.**

In so many health systems, organizations, and health professional groups, communities and jurisdictions compete for "market share" of the resources spent on healthcare. In publicly funded systems, they compete for finite resources to fund their particular agency, organization, health profession, or service delivery model. In privatized health systems, they compete on market share directly and aspire to attract consumers to their organizations to drive revenue. Health systems compete most commonly on their achievement of clinical outcomes (disease focused outcomes, performance metrics such as safety and quality) to make the case that they are offering the "best care available". Yet, using the current measures of clinical outcomes, populations achieve little in terms of meeting their health and wellness goals. Simply put, key stakeholders within health systems compete with each other for resources and funding. Unfortunately, what these stakeholders compete on are of little value to the population they are serving, and far worse, the competitive nature of health systems incentivizes a very siloed. In order to achieve

personalization of a health system, stakeholders and organizations across the health system have to collaborate, not compete, in order to achieve value for populations they serve.

Consider the situation of an elderly woman who is experiencing severe pain and limitations to mobility due to osteoarthritis in her knees. The most likely solution to improve her wellness and quality of life is to undergo a knee replacement to remove the severe pain and restore her mobility to regain her independence. In a personalized health system, she receives an overall wellness score that will not only depend on the hospital experience and clinical outcome of the knee surgery, it will also depend heavily on the supportive services she receives at home during her recovery and the access to physiotherapy to ensure she is able to regain her mobility effectively. The wellness score will be the cumulative sum of the efforts of organizations across the continuum of care, the hospital, the primary care follow up, the community rehabilitation, and the community level supportive services necessary for her to restore and improve her quality of life, health and wellness. In the current, competitive health system environment, there is very little interaction or collaboration across the continuum of care as each agency or health provider is focused solely on their individual contribution to the woman's recovery. It is difficult to understand how this type of model could provide optimal care when one provider is not informed about the motivations of another, and neither are trained, encouraged or incented to take into account the health and wellness goals of the patient. In a personalized health system, each of the contributors to this woman's recovery would be integrated and would collaborate as a team to efficiently and effectively restore this woman's quality of life, while focusing on her unique and personal health and wellness goals

- to remain independent at home, to continue to care for her pets and eventually re-join her bridge club when she regains her mobility.

In order to achieve this type of team synergy, funding models (such as Accountable Care) must incentivize the collaboration. Currently, fee for service or pay for quality models incentivizes competition among health organizations and provider teams, where the group with the largest volume of services delivered achieves the greatest revenue. To personalize health systems, this antiquated model of funding service transactions needs to shift to funding outcomes that are targeted for specific populations and aligned with value. In this model, health providers, teams, and organizations only receive funding when both the short-term and long-term priority outcomes are achieved; how they are achieved by the various provider groups is of little consequence. When outcomes are funded, rather than services delivered, health professionals or health organizations will have to collaborate to figure out the most efficient and effective process for achieving population targets. In essence, funding is tied to achieving the outcomes articulated by individuals and populations as valuable to them.

In many health systems, the integration of services has been identified as necessary to reduce high rates of utilization of health services in order to bend the cost curve. However, the integration of health services is challenging when all of the members of the continuum of care are competing with each other for health system resources or market share across regions. Territorialism and the protection of "turf" all work against collaboration. Consider the possibility of incentivizing collaboration among stakeholders across the continuum of care by creating currencies (i.e. allocating resources) based on achieving wellness outcomes for individuals, communities, and populations. It is useful to consider a practical example of how this could work.

A community is experiencing unusually high rates of Chronic Obstructive Pulmonary Disease (COPD) resulting in poor workforce productivity (economic hardships), high rates of sick time and absenteeism in the local workforce. The hospital utilization data reveals very high numbers of adult men seeking care in

the emergency department for significant respiratory symptoms consistent with high rates of COPD. In the current system, resources are allocated to each agency across the continuum of care to deliver a set level of services in a transactional model: fee for service is the currency for the specialist; global budget allocations for the hospital; and, varying funding models for community agencies. In a personalized system, currencies (or resource allocation) would fund health systems that serve a defined region or community and would be allocated for bundled services that address wellness needs of the population the system serves. The allocation of funding would focus on achieving specific metrics personalized to the community priority of respiratory wellness. Personalized (bundled) services would include programs aimed at prevention of COPD in young adults, services to provide best available management of COPD to people with this diagnosis 24/7, and services that ensure adequate rehabilitation based on best practice guidelines would be available in the community. The combination of services could only be achieved through collaboration from "hospital to home" among all of the agencies responsible for programs and services who share the collective goal of restoring respiratory health, preventing reoccurrence of exacerbations, and eliminating (or reducing) new cases of COPD in the community. This bundled currency approach personalizes the system as it incentivizes the key stakeholders within the health system to work together to achieve the community priority health goal, while at the same time removing the territorialism and competition in competing for limited health system resources.

To achieve Step Five, currencies (resource allocation) must incentivize collaboration across specialists in the hospital, community based organizations, primary care, and workplace health programs to collaborate to personalize service delivery to achieve wellness at the community level and the achievement of individual health goals at the personal level.

### **Step Six: Join the 21<sup>st</sup> century, and get connected.**

People are "connected" to the world around them using digital tools, apps, and platforms to conduct their banking, to arrange travel, to purchase retail goods, and to engage their social networks to learn and participate in day to day interactions. The only sector to which people cannot connect using digital technologies at a system level is healthcare. The analysis of mobile apps presented in Section Two revealed that people extensively use online tools and technologies to self-manage their personal health and wellness. The challenge is that they do so independently and have no ability to connect their personalized goals and wellness activities to their interactions with their health providers. Essentially, consumers are designing and engaging in self-management of their health and wellness, yet they do not have the advantage or benefit of engaging in self-management with the support and expertise of their health provider or health team. Currently, there are two "health systems" for most populations: the formalized system that offers primarily disease and illness management; and, the "digital health system" that people customize to meet their personalized needs for self-management of health, wellness and quality of life.

In order to personalize health systems, the key stakeholders in these systems need to connect more directly, and differently, to the populations they serve, using digital tools and platforms. Health systems need to connect to consumers where they are (online, digitally), rather than continuing to expect and require that consumers "come to the health system", in order to seek the support and expertise of health providers. In a personalized health system, health teams would transform their practice structure to directly engage people using digital tools that connect to the tools the individuals are already using to support self-management of health and wellness. As an example, in a personalized health system, the 38 year old woman who has been just been diagnosed with Type II diabetes has downloaded three apps on her smart phone: one to track insulin doses and A1C levels; another to access personal training to

achieve personal fitness goals through exercise; and, an app that offers calorie counts and menus to manage her diet. Periodic visits with her care provider (physician or diabetes educator) are supplemented or replaced by regular online monitoring of progress in real time using the tracking outcome data on the apps. Interactions between the person and provider are conducted virtually through email, Skype, and texting both when the person needs input into their health and wellness program and when the provider is "fagged" or alerted by the system when biophysical measures are indicating a decline in the person's health status. Imagine how diabetes care might change into a personalized system whereby providers have online access and engagement with their patient's health and wellness program, and use digital technologies to reach out to support, encourage, and intervene when it is needed, where it is needed, and when it is needed, to support individuals to achieve their wellness goals.

We are not suggesting that providers are not digitally savvy, nor are we suggesting that there is not a movement to integrate new information technologies into practices. However, we are suggesting that there is significant silos between the use of online technologies by providers and individuals and there are few examples of how the two are integrated. There is a huge opportunity to augment and personalize care plans by taking advantage of data being gathered by people on their own. In a personalized health system, health providers and teams partner with their patients to support the achievement of individual's health and wellness goals using digital technologies to set health and wellness goals, track progress towards meeting those goals, and engage when and where it is needed to support success.

Personalization of health systems can be achieved by using the same approach that Facebook, LinkedIn Twitter, and other technology platforms have achieved in connecting people to the world around them. Digital tools put into the hands of care providers, with all of the security and privacy features used in other sectors (i.e., banking), connecting the care and services (re-designed to achieve connectivity to people) present an enormous opportunity to create personalized programs of health and wellness. It does not mean that digital strategies should be added on as another layer over top of the existing antiquated system. Personalization simply means that healthcare systems are connected to the population they serve more directly by leveraging digital technologies to understand and support the health and wellness goals of individuals, and designed specifically for professional practice and services to support people to be successful in achieving health and wellness goals.

A good first step in joining the 21<sup>st</sup> century technology revolution is for health systems to design strategies (i.e., online portal connections, or communication links to health information collected using digital tools) that connect to the health and wellness programs people are already using, and then tailoring the digital linkage so that the person identifies what information and outcomes they want to communicate to their provider, and together decide how the provider can best support them to achieve their health and wellness goals (i.e., via email dialogue, or "Skype clinic" approaches, or monthly tracking of progress online), rather than waiting for health to deteriorate and require acute intervention in emergency type situations.

As health teams take advantage of technologies to assist in designing strategies for connecting to their patients in a more personalized manner, the practice structures and facilities will adapt and shift towards a more "connected" healthcare system that is meaningful to the personalized needs of the population they serve.

**Step 7: Democratize information to empower people to take charge of their health and wellness.**

Many health systems work within information structures where the personal health information of individuals is held in "secure" information vaults managed by health system organizations or stakeholders. For example, it is common that all hospital visits/interactions are recorded in a patient record in which information is collected using a combination of paper-based and digital information systems, housed and securely stored in hospital databases. Primary care teams use paper or digital health records to document patient visits and test outcomes which are then saved in health information practice filing systems. Similarly, community organizations house and store patient health information within their clinical information systems to capture utilization outcomes, and service delivery quality outcomes. In many health systems, all personal health information is managed autonomously by each of the health organizations in the system, with little or no ability to cross-reference their information with the other players in the health system. This not only creates unnecessary duplication, it does not allow for all of the pieces of an individual's health outlook to be considered in tandem. In the majority of current healthcare systems, personal health information (i.e., lab results, diagnostic testing outcomes, clinical assessment measures, and medication management) are the responsibility and purview of the health system stakeholders; they are not available to the very people the information is about, who require the information to make informed decisions about health, wellness, and quality of life.

In a personalized health system, information about the health of individuals, communities, and populations is made readily available, easily and effectively for the primary purpose of equipping the individual/community/population with the information they need to make informed decisions and choices in real time. Consider the 48 year old woman who is the primary caregiver and decision maker for her elderly mother with Alzheimer's disease. In a personalized health system, the daughter and her mother would access their personal health information when required on their mobile device or computer, allowing them to share data and insights with all partners in their healthcare team. This creates the condition for informed discussions by all parties as well as an ability to directly monitor progress over time to determine whether previously defined health and wellness goals are being met. During each visit to a health provider, the health information collected, assessed, or communicated by the health team is downloaded onto an electronic platform or "app" for the woman so that she has a record of the discussion, the decisions, and the assessment of her mother's health. This personalized approach then empowers the woman to directly engage other health providers when necessary, share accurate and up to date information with them about her mother's health status and wellness goals, and make informed decisions based on accurate and detailed health information, available on an accessible digital app or platform.

The democratization of information is also important for communities and populations. Consider the example of a community which is engaging in dialogue about health system challenges and the realities of fiscal resources in a publicly funded system. In a personalized health system, communities have access to health information about the current health and wellness of their community and the population health priorities of the population who lives in or near the community. In a personalized system, communities are actively engaged in a dialogue with health system organizations and have direct input into the challenging decisions health organizations are often faced with. In such a system, communities receive information regularly about the health and wellness of the community, the clinical outcomes the health system is achieving, the utilization of health services, and the health and wellness priorities of the population. Citizen dialogue, informed by the democratization of information, enables communities to engage with health system leaders to provide insights into population values, and builds community awareness of the challenges health systems face. An engaged community informs and supports health system leaders to make decisions that personalize the system structures and programs to the unique priorities, needs and values of the communities they serve.

Engaged citizen dialogue enables health system leaders to build meaningful relationships with communities as health system "shareholders", to ensure the health system is delivering on the value proposition they are mandated to achieve by the taxpayers who pay for the system. However, it is only possible when there is transparency in terms of population level health data that is available in real-time, and in a way that is easily accessible and understandable by populations.

**Step Eight: Learn from industry and customize healthcare to the needs, expectations and values of the population.**

Health systems have been delivering health services using a "one size fits all" approach where access to services is organized by disease, illness, or injury a person is experiencing. People have little or no choice in how they access health services or how those services are delivered (options are limited to clinic visits, the primary care office and emergency department). However, growing numbers of people are designing and customizing their own healthcare using online tools, programs and digital platforms. Why? Because health systems are not structured to achieve what matters to people. Health systems need to learn from other industry sectors to customize their services to the needs and expectations of the people they serve.

The first lesson that can be adapted from industry is to use market segmentation to identify the desires and commonalities of sub-sectors within populations. Programs and services can then be tailored in a way that reflects these insights. The second lesson is to design new ways of accessing health services (i.e., "distribution channels") that respond to the requirements and preferences to each population segment. This could include:

- a. An in-person clinic or MD visit, online consultation, telephone call, or home visit;
- b. The use of secure messaging systems to book appointments, receive diagnostic test results, request referrals, and receive notifications to enhance prevention (i.e. flu shots);
- c. Online and text-based scheduling and appointment notifications for changes or delays;
- d. An "email" clinic where the health professional or health team is online and available for consultation; and,
- e. Videoconference or Skype specialist appointments (i.e. "teledermatology" where the person takes a picture of the skin lesion and emails it to a dermatologist for an opinion).

To date, health systems have organized services and programs by disease groups and the access to these services relies almost entirely on in-person visits to the program. A personalized health system would be customized to fit each segment in the population and offer choices in terms of how people can access these services. For example, segmenting the population by demographics (i.e. age, gender, geography, or employment) is a simple way to categorize and then customize access to services. In a personalized health system, access to "in person visits" or home visits may be the most likely preference of seniors, whereas online appointments and secure messaging would be the most convenient access strategy for busy, working mothers. Offering choice and customization of health services and health system delivery mechanisms enables people to design the care strategy that best suits their needs, values and lifestyles.

How would health systems achieve a customized approach? Consider the health system which is challenged to meet the needs of aging populations, predominantly rural, with growing numbers of elderly citizens who are experiencing a range of chronic illnesses which are challenging to manage. In a personalized health system, the population could be segmented based on age and geographic setting in order to better respond to the values and expectations these seniors have for their health system. The segmentation is also cross-referenced with health utilization and clinical outcome data, and social services data in order to profile typologies or groups within the senior population to identify unique priorities and values. Health services would then be designed based on goals for health, wellness and quality of life, including wellness targets such as "living independently in my home", "engaging in community social activities on a day to day basis", and "remaining within the home community" to be a part of family and friends social networks they have grown up with. The health team would provide a menu of choices for how services could be accessed and delivered in order to customize care to meet the needs of the senior, their family, and community. Seniors who prefer to remain at home and access "Skype" visits with their doctor would have the choice to do so and would be provided with technology support if required. The care team in the rural community would use digitally connected health to track and monitor medications, appointments, activity, and socialization with the seniors to help them remain independent and achieve their wellness goals. Prevention and wellness would be priority outcomes for health teams who collaborate together (both in person and remotely with specialist teams) to partner with seniors and their families to achieve their wellness goals.

Personalized health systems are mandated to deliver value to the populations they serve; to achieve that mandate they need to recognize that there are wide variation across population sub-groups who have different needs, expectations and values which all require different approaches to how health services are structured and accessed. In a personalized system, customization and segmentation are enabled by accountable care funding models through which health teams are funded to achieve outcomes for defined populations and to meet priority health outcomes using a coordinated, customized approach to health service delivery that recognize what matters to people.

### **Step Nine: Put the population in charge of defining value.**

Every health system in the world is struggling with the increasing demands for health services and managing the growing costs of delivering services where and when they are needed. Funding resources required to sustain health systems are rapidly outpacing the GDP growth in most countries, placing health systems in the challenging position of making decisions to fund, or not to fund, certain types of healthcare services. This is exacerbated by the rapid advancement of science and technology which offer new and innovative therapies, devices and treatment options, including genomic-based therapies for disease management or cure. These therapies come at an extraordinary cost and will lead to very difficult conversations and decisions about how and where health systems allocate their resources.

Elected officials who oversee health systems walk a fine line to ensure they offer services populations need and desire, while at the same time managing fixed budgets within which they must be able to deliver said services. In the current health system, health leaders and decision makers focus primarily on cost cutting initiatives to achieve the maximum possible productivity, efficiency, and quality within limited fiscal resources. To date, many populations around the world have questioned the value health

systems are delivering to populations as prevalence of chronic illness continues to grow, and demands for services continue to escalate.

In a personalized health system, it is clear that health system costs and demands for health services will still require very challenging choices. The only question is how these decisions are made within the mandate of delivering value to populations the system serves. In a personalized health system the population is actively engaged, using citizen dialogue to advance discussions around how to achieve value for the population. The personalized health system essentially puts the population in the role of a decision-maker collaborator in making the difficult decisions about what services are provided and what services are not provided, what outcomes the funding models will pay for, and what population outcomes are abandoned when they do not achieve value.

Citizen dialogue structures are embedded deeply within a personalized healthcare system and are used to achieve the following:

- a. Fully understand and maintain a clear focus on population value for all decisions;
- b. Inform and debate decision options with citizens to ensure the population understands what is possible and what options are viable (viable defined as feasibility of costs and the system's capacity to deliver a service or program) when making difficult decisions on what services to offer and what services/programs can no longer be offered;
- c. Engage citizens in determining the best way forward when making difficult decisions so that the population has a voice, and has meaningful input and therefore buy-in into decisions that will clearly impact every citizen in a significant way; and,
- d. Build health system literacy across the population, and across health system key stakeholders (including hospitals, community organizations, health professionals, private industry, policy makers/government, communities/regions/citizens) to engage in healthy debate and decision-making that is informed, and reflective of the values of populations, which is centrally important in any decision made at the health system level. Health system literacy ensures that health system decisions are made collaboratively with key population stakeholders in order to stay true to the population's values within the understood limitations and constraints that health systems operate.

Citizen engagement in health system level dialogue and decision-making is a necessary and foundational feature of a personalized health system that supports the transformation of health systems from one that is rather narcissistic, focused on the system, its processes, providers and clinical outcomes, to a personalized system that focuses on outcomes tied to the value it delivers to the population it is mandated to serve. Consider the example of the health system that deems "healthy aging" as the priority the health system will achieve over the course of a five year mandate. The health system leader in most jurisdictions defines "health aging" as the priority health challenge to address, based on evidence in the literature and population demographics. Health system leaders then design the implementation strategy across the entire healthcare system, allocating the necessary resources to achieve their defined objectives. In a personalized health system, citizen engagement processes would enable and support dialogue between key citizen groups and health system leaders. . Citizen dialogue that includes representatives of the population sub-sectors engage in dialogue to determine priority outcomes for the

target population. Services are then personalized to fit with the needs and priorities of the target population that achieve wellness outcomes deemed important and worthy through citizen engagement.

Thus, a personalized system determines population priorities and strategies to support achieving wellness outcomes by engaging the impacted citizens directly in designing the strategy, focused on using a values-based approach to determine what support is needed, how it should be delivered, and what it is designed to achieve in terms of wellness and quality of life.

### **Step Ten: Measure what matters.**

Health systems today focus on measuring performance and quality largely in terms of measuring the performance of the health system, rather than measuring whether the system is achieving value for the populations they serve. Personalizing a health system means that the current system-level metrics need to be augmented and strengthened to include metrics which reflect values of the individuals, communities and populations served by the system. Measuring value at the individual, community and population level will require creating new metrics to measure progress on a health system's ability to achieve value through personalization. A personalized system will reflect the idea that people and populations are the key to ensuring success.

The metrics for a personalized health system are as follows:

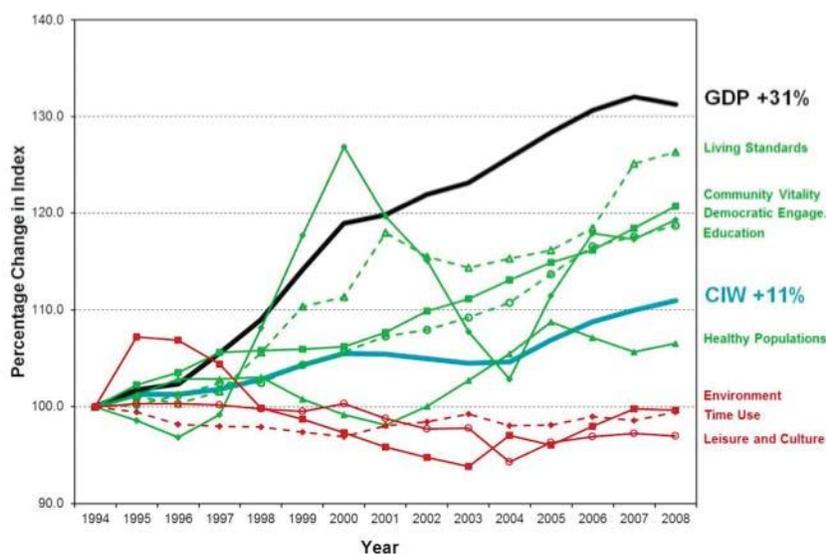
- 1. Person-level metrics:** Person-specific metrics would include what health systems measure now (i.e. biophysical measures such as A1c levels for diabetes care, blood pressure for cardiovascular health), but also add on health and wellness goals established by the person. This is the route to get people tied into their treatment plans as the metrics would be theirs rather than those purely of the clinician. For example, when considering the pre-offered range of treatment options, the person with COPD would decide on a plan with a level of exercise tolerance most closely aligned with their personal values. A person's values can be something as simple as being independently able to answer the door or walk around the grocery store. Including person-level metrics will personalize treatment plans, making it much more likely for people to take ownership of their care plan, as they have decided on goals they feel are achievable and offer value to their lives.
- 2. Population health metrics:** These are key indicators of health and wellness of a population that reflect values such as quality of life. System-level utilization metrics mapped onto the population level outcomes can be used to determine the allocation of health system resources and patterns of utilization that achieve outcomes. These metrics act as a suite of currencies and start to bind the providers of care to the population. This is achieved by focusing on big system changes over populations where the expectation is that certain standards need to be met by all, and payment to system partners and providers is directly linked to achieving priority population health outcomes. For example, immunization for flu is a major predictor of hospitalization and illness in seniors. Population health outcomes would be identified through community engagement to define realistic immunization targets that are valued by the population. Groups within the population have varying health priorities; thus, health systems would define key population health metrics using segmentation to define value within each to achieve value. System-wide utilization metrics are the most dominant type of metrics in

global health systems; however, they need to map onto the population health metrics to define the value health systems are achieving for populations. The economic metrics for the health system would provide evidence of cost versus value relative to population outcomes. For example, looking at emergency admissions on a practice by practice basis would enable provider teams to more effectively manage health outcomes at the population level to understand change over time.

To create a system that includes both person-level and population metrics simultaneously, we suggest returning to our concept of salutogenics, discussed earlier in this paper, which presents the health journey as one analogous to a river of life. Salutogenic metrics would include a very short questionnaire which is filed by the person at the beginning and end of an accounting period in order to achieve a measure of population wellness. The concept of population wellness is a measure that has been used in a number of countries and could be achieved by developing scales that are similar to the Edinburgh Warwick scale which has been used extensively (<http://www.healthscotland.com/uploads/documents/3052-WEMWBS%20scale.doc>). Currently, health systems measure and manage clinical outcomes and system performance (i.e. safety, quality, access), but do so in isolation of whether the health system is achieving value in terms of wellness and quality of life. Consider the situation where the health system is achieving the highest quality of best practice management of disease and illness, yet the population they are mandated to serve report declining levels of self-reported levels of wellness.

In Canada, the Canadian Index of Wellbeing is a tool that defines and measures wellness on eight different domains. An example of trends in the Canadian Index of Wellbeing is provided in Figure 3.

**Figure 3: Trends in the Canadian Index of Wellbeing and its Eight Domains Compared with GDP (1994 to 2008)**



Source: Canadian Index of Wellbeing, 2012, downloaded from: [https://uwaterloo.ca/canadian-index-wellbeing/sites/ca.canadian-index-wellbeing/files/uploads/files/CIW2012-HowAreCanadiansReallyDoing-230ct2012\\_0.pdf](https://uwaterloo.ca/canadian-index-wellbeing/sites/ca.canadian-index-wellbeing/files/uploads/files/CIW2012-HowAreCanadiansReallyDoing-230ct2012_0.pdf)

Despite well documented wellness measures in many global health systems, wellness is generally not linked to health system performance. Health systems at local and regional levels are not integrating measures of wellness in regional or community levels to inform and support personalization of health system services and outcomes. To achieve personalization of health systems, measures of wellness must be integrated into health system performance outcomes to allow for the direct comparison of health system performance relative to wellness of the population they are serving.

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