



How are evidence-based recommendations for disease prevention implemented?

Gordon O Matheson^{1,2}, Holly O Witteman^{3,4,5}, Terry G Mochar⁶

About the AUTHORS

¹Division of Sports Medicine, Department of Orthopaedic Surgery, Stanford University School of Medicine, Stanford USA

²Human Biology Program, School of Humanities and Sciences, Stanford University, Stanford USA

³Department of Family and Emergency Medicine, Faculty of Medicine, Université Laval, Québec City, Québec, Canada

⁴Office of Education and Continuing Professional Development, Faculty of Medicine, Université Laval, Québec City, Québec, Canada

⁵Research Centre of the Centre Hospitalier Universitaire de Québec, Québec City, Québec, Canada

⁶Former Managing Director, Reckitt Benckiser Worldwide

Contact:

Gordon O Matheson
gord@stanford.edu

Certain problems in health care are referred to as complex – preventable chronic disease is certainly one of them. It is nothing short of amazing to consider that 45 years have passed since the Executive Board of the WHO predicted that cardiovascular disease, a major portion of preventable chronic disease, would become one of the greatest epidemics humankind has faced (1). Forty-five years later, non-communicable diseases (NCDs) are the dominant health challenge globally, accounting for 63% of deaths worldwide (2). Moreover, the problem is no longer predominantly in Western cultures. 80% of NCD-related deaths, especially premature deaths, occur in low- and middle-income countries (2).

This apparent lack of progress is by no means from lack of effort. Consider the many disease prevention initiatives, across multiple sectors, directed toward specific populations over the last four decades (Table 1). Despite these efforts, the morbidity and mortality from preventable chronic disease continues to increase. While remarkable, advances have been made in *other* fields of medicine over the *same* period of time, these advances have mainly been in single-system diseases. Chronic disease, because of its complexity, presents a particularly stubborn problem. With that understanding comes the realization that additional approaches are a rational way to proceed if we hope to make progress in the prevention of chronic disease.

Table 1 Types of efforts in disease prevention

1. Compiling Scientific Research
 - a. Epidemiological data (risk factors, efficacy, effectiveness)
 - b. Evidence-based recommendations
 - c. Implementation science
2. Public Health Initiatives
 - a. Health Promotion
 - b. Prevention Advocacy
 - c. Wellness Programs
3. Policy & Regulations
 - a. Government
 - b. Major non-governmental organizations
 - c. Health care industry
 - d. Food industry
 - e. Tobacco industry
4. Teaching & Education
 - a. Degree granting institutions
 - b. School curricula
 - c. Medical conferences and publications
 - d. Parental guidance
 - e. News media – print, television, internet
5. Personal Counseling
 - a. Health care professionals
 - b. Fitness industry professionals
6. Site- or Context-Specific Programs
 - a. Work place
 - b. Physical education
 - c. Health care facilities, programs, services
 - d. Sport venues and programs (“sport for all”, “everyone’s an athlete”)
7. Built Environment
 - a. Urban planning
 - b. Active transport
 - c. Community facilities
8. Technology
 - a. “Apps” (applications)
 - b. EMR (electronic medical record)
 - c. Big data



New thinking for a complex problem

Heng makes the case that complex problems do not lend themselves well to reductionist thinking (3). Unfortunately, that can present a ‘thinking’ problem in itself for those of us steeped in the data-driven, analytical approach to medical science. Reductionism has been so successful in so many areas of medicine that it is difficult for one to get one’s mind around a different approach. But the signs are unmistakable – we must do so to prevent chronic disease. Accumulating scientific evidence about the relative impacts of a myriad of independent variables has not been the answer to reducing the morbidity and mortality from chronic disease. Innovation is critically needed at the interface between intervention efficacy and effectiveness for the four chronic disease risk factors: diet, exercise, alcohol and tobacco.

One possible reason for the lack of innovation in disease prevention may be that risk factor reduction requires behavioral change. By and large, health care providers view behavioral change as the purview of the patient (4). Therein lies the key to innovation. To what extent have efforts within the clinical community focused on determining what matters most to people/patients, and therefore, what governs their behavioral choices?

Analysis of the Status Quo

Without innovation, we remain tangled in the many tentacles of status quo, unable to disrupt the static landscape of disease prevention. The resulting hesitancy and ambivalence (if not outright hopelessness) has created longstanding, observable characteristics that define the current landscape in disease prevention (5).

One characteristic is blame; the tendency to displace accountability for the problem of disease prevention. The targets of blame are multiple, most commonly the health care industry, medical school education, the food industry, governments or patients. The result is an accountability fog that leads to further fragmentation rather than the interdisciplinary collaboration required for complex problems. Another characteristic is fuzzy strategy. Recommendations and guidelines for disease prevention, published by influential global organizations, are typically at a high level of abstraction and thus, non-actionable. National, regional, and local health care agencies, taking their lead from global exemplars, default to the same abstraction-inaction archetype, providing intervention implementation strategies at the level of the end-user (person or patient) that are vague and non-actionable. A third is desperation; a sort of ‘doubling down’ or continued preoccupation with top-down approaches that are known to be ineffecti-

ve. This gives rise to improbable ideas and misdirected solutions aimed at merely improving and expanding existing approaches or calling for arcane sweeping societal changes outside innovation’s locus of control (6). A fourth characteristic is perpetuation of the status quo through misplaced trust in industry experts whose motivations may include avoiding disruption of favorable economic conditions currently in place within health care. Finally, while technology will surely play a major role in disease prevention strategies, the current default to technology is premature in our innovation process. Why? Because technology is most effective when it solves an underlying human problem and that first requires the human problem to be fully understood.

Taken together, these five characteristics comprise the current landscape in disease prevention. In order to begin to change the mindset hidden beneath this landscape, health care providers must come to the realization that disease prevention is not a ‘knowing’ problem. It is a ‘doing’ problem. Human behavioral change is the core issue, not just for patients, but underlying the mindset of every single person whose path crosses the path of those with preventable chronic disease. Crossing the knowing-doing gap is difficult at the best of times. Without innovation, it becomes impossible.

Human-centered design is innovative

Other literature has addressed the key advances and contributions of fields such as Public Health, Behavioral Science, and Implementation Science in preventing chronic disease. In addition to these, there is a less well-known approach more frequently found outside the health care industry. For the last several decades many industries have used a form of Design Thinking, known as Human-Centered Design (HCD), to understand the factors that govern behavior and choice in potential customers. HCD is a scientific approach using methods within a process to determine end-user needs. In effect, HCD is a systematic approach that meets people where they are, and designs systems, processes or products to help them get where they want to be. HCD holds promise to drive the ‘doing’ part of preventable chronic disease prevention, thus implementing the ‘knowing’ drawn from evidence-based recommendations.

HCD is a creative and scientific field devoted to adapting systems to the people who will use them, rather than requiring people to adapt to the systems (7-11). HCD addresses human limitations by creating designs from insights gained through empirical study of the people who will use a system or product. It is a phased, iterative process, in which individual designers or



design teams use established methods to develop systems, programs, processes or products that are suited to the people who will use them. These methods often include systematically observing people's natural tendencies; understanding and empathizing with people; eliciting their goals; developing rough, preliminary designs to help people meet their goals; collecting data of various kinds about how people use, do not use, or are unable to use the preliminary designs; and revising designs according to these data.

HCD might be thought of as an expansion of motivational interviewing, a style of interaction already in use in medicine to help people align their behavior with their health goals. Motivational interviewing is defined as, "a collaborative, person-centered form of guiding to elicit and strengthen motivation for change (12)". Like motivational interviewing, HCD is oriented around individuals' goals; however, HCD goes beyond motivation by also incorporating other aspects relevant to each patient and by involving people, patients, health care providers and others in the co-design of physical prototypes or defined processes. Perhaps the most important distinction is that HCD is explicitly iterative in response to data from people's reactions to prototype designs. Although it would be wonderful if every design achieved its objectives on the first try, more often, first attempts fail. The crux of HCD is to systematically learn from early failures as quickly as possible in order to reach success sooner than you might otherwise. This philosophy is often dubbed, "Fail early, fail well," or, "Fail forward".

HCD complements approaches currently being used for disease prevention and makes a critically important addition by focusing on the unique needs, context, goals, desires, strengths and limitations of the end-user and by testing prototype designs early and often in iterative design cycles. Designing solutions with human end-users increases the chances that the solutions will be suited to them, thus increasing the chances of success.

Implementing behavioral design

There are two important questions to be answered in order to advance HCD as a method for reducing the morbidity and mortality of chronic disease. The first is whether or not the methods and processes of HCD can be taught to a large mass of people within a relatively short period of time (often referred to as 'scalability'). The second concerns whether or not success in disease prevention is associated with a widespread shift in the way we think about chronic disease (referred to as 'mindset').

The first question concerns the likelihood of changing the mindset in disease prevention through the creation and dissemination of appropriate web-based training programs for HCD. An example, from recent history, is the wide-scale adoption of new training programs for the pre-hospital care of trauma victims (Advanced Trauma Life Support). 40 years ago, an orthopedic surgeon by the name of Jim Styner, crashed a small aircraft he was flying into a field in Nebraska. His wife died immediately and three of his four children were critically injured. Jim found that pre-hospital emergency care was inadequate and inappropriate and set out to make changes. Advanced Trauma Life Support, the program Jim helped to build, has now been adopted by more than 60 countries as the standard of care for both pre-hospital and trauma center settings. A similar approach for cardiac arrest, stroke and other non-traumatic collapse, Advanced Cardiac Life Support has been equally successful in changing the mindset about pre-hospital care for non-traumatic life-threatening emergencies.

If we were to provide standard training in design for the target audiences that intersect with the preventable chronic disease trajectory (health care professionals, health care administrators, medical researchers, medical product designers, medical insurance companies, patients, and families) many small-scale interventions, programs and products could be created, tested and iteratively refined to identify designs that may be effective on a larger scale (5). This would create products, programs and services that work for people rather than expecting people to adapt to ill-fitting systems. Fostering widespread use of HCD methods for disease prevention, we might achieve widespread adoption of a human factors approach. In the same way that Advanced Trauma Life Support does not require a definitive diagnosis in the trauma patient, disease prevention advocates that functional capacity rather than a specific clinical diagnosis would be the entry point for preventive measures (10). Widespread implementation of this approach would help to change the mindset from disease to prevent and from cure to functional capacity.

The second question concerns whether or not a shift in mindset is a sufficient catalyst to change the outcomes for preventable chronic disease. At present, chronic disease is viewed as disease-based: abnormal single system pathobiology that fits a reductionist disease model for diagnosis and treatment. If a patient has several of these diseases (most do), he or she is referred to as having multiple co-morbidities. But, as argued above, the reality is that chronic disease requires emergent



rather than reductionist thinking; in short, a shift in mindset.

An example of a major shift in mindset that took place in 20th century England is the hospice movement. End of life care was characterized in many medical reports as abysmal, but the health care system proved unable to respond. A British nurse, Cicely Saunders, held tightly to the belief that terminally ill patients need compassionate care that is both medical and also addresses their fears and concerns for physical comfort. She dedicated her life to her belief, meeting substantial resistance that resulted in her obtaining additional training as a medical social worker and also as a physician, in the hope her ability and credibility would help to surmount the resistance. Hospice is now available in hundreds of countries and is supported and advocated by the World Health Organization. Knighted by Queen Elizabeth in 1979, Dame Cecily Saunders' work provides an example of a major shift in mindset.

Prevention by design

In a similar way, a mindset change in chronic disease is possible. Some indicators that this is taking place already exist; most notably the shifting demographics associated with an aging population and the media attention given to this. Because HCD uses an approach that is different from but complementary to data-driven, top-down approaches, an opportunity to close the knowing-doing gap exists. For disease prevention, we already have the "what" needs to be done. What is missing, and where innovation is required is the "how" do we do it.

Disease prevention is more of a human problem than a purely scientific one (13). The lack of progress in reducing the morbidity and mortality of chronic disease indicates that another approach is needed, one that takes individual human needs, concerns, goals, abilities and limitations into account. Fortunately, HCD is available as a method to provide just that.

References

- (1) World Health Organization Regional Office for Europe. The prevention and control of major cardiovascular diseases: report on a conference. Euro 8214. In. Brussels: WHO Regional Office for Europe; 1973.
- (2) Ala Alwan, Tim Armstrong, Douglas Bettcher, et al. Global Status Report on Noncommunicable Diseases 2010. In: World Health Organization, ed.; 2011.
- (3) Heng HHQ. The Conflict Between Complex Systems and Reductionism. *Journal of the American Medical Association*. 2008; 300:1580-1581.
- (4) Jallinoja P, Absetz P, Kuronen R, Nissinen A, Talja M, Uutela A, Patja K. The Dilemma of Patient Responsibility for Lifestyle Change: Perceptions Among Primary Care Physicians and Nurses. *Scandinavian Journal of Primary Health Care*, 25:244-249, 2007.
- (5) Matheson GO, Pacione C, Shultz RK, et al. Leveraging Human-Centered Design in Chronic Disease Prevention. *American Journal of Preventive Medicine*. 2015; 48:472-479.
- (6) Matheson GO, Witteman HO, Mochar TG. Disease Prevention: What's Really Important? *British Journal of Sports Medicine*, 2015. Published Online First doi:10.1136/bjsports-2014-094261
- (7) Brown T. Change by design: how design thinking can transform organizations and inspire innovation. 1st ed. New York, NY: HarperCollins Publishers, 2009.
- (8) Luma Institute L. A Taxonomy of Innovation. *Harv Bus Rev*. 2014; 92:30-31.
- (9) Liedtka J, Ogilvie T. Designing for growth: a design thinking tool kit for managers. New York: Columbia Business School Pub., Columbia University Press, 2011.
- (10) Matheson GO, Klügl M, Engebretsen L, et al. Prevention and management of non-communicable disease: the IOC consensus statement, Lausanne 2013. *Br J Sports Med*. 2013; 47:1003-1011.
- (11) The Field Guide to Human-Centered Design, 1st Edition. IDEO.org, 2015. ISBN: 978-0-9914063-1-9
- (12) Miller WR, Rollnick S. (2009). Ten Things That Motivational Interviewing is Not. *Behavioural and Cognitive Psychotherapy*, 37:129-140, 2009.
- (13) Matheson GO, Klügl M, Dvorak J, et al. The Responsibility of Sport and Exercise Medicine in Preventing and Managing Chronic Disease: Applying Our Knowledge and Skill is Overdue. *British Journal of Sports Medicine*, 45:1272-1282, 2011.