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Response from the Stanford Center on Longevity to the United States Senate Committee on Finance Chronic Care Working Group

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Introduction

The Stanford Center on Longevity applauds the Senate Finance committee's creation of a chronic care working group and encourages the group to think broadly about the roots of chronic diseases as well as treatments. The dramatic reduction in premature death in the 20th century is among the greatest achievements in history. At the same time, the resulting near doubling of life expectancy presents society with an entirely new set of challenges. As the Committee points out, chronic diseases are among these new challenges, which compromise quality of life and overburden financial resources for individuals and the nation.

First and foremost, it is important that we do not accept the steep rise in chronic diseases as inevitable. We must not equate these conditions with "aging" any more than our ancestors accepted rickets and pellagra as normal parts of life. Rather we must understand new challenges and address them. Unlike acute diseases, chronic conditions result from a lifetime of choices and thus solutions must consider not only management of conditions once they arise, but modification of behaviors that lead to these diseases in the first place. Effectively addressing conditions that involve behavioral and life-style choices demands an investment in behavioral science as well as biomedical science.

Fortunately, recent developments in technology are providing scientists and designers with previously unimaginable tools to encourage people to lead healthier lives by intervening in personalized ways. Individualized approaches have entered the marketplace with stunning speed and technological advances in measurement are becoming daily occurrences. No doubt, such technologies will be part of the solution. We are concerned, however, that they are most effective with the healthiest and best educated subsets of the population. There is substantial evidence that such approaches alone will be ineffective in addressing population health. Social norms must change. Engaging in conversations with children about fitness and obesity, marketing healthy lifestyles to older as well as younger adults, rethinking attitudes about food, and developing appealing alternatives to traditional high calorie "comfort" foods, will be required at all levels of the population if we are to solve these challenging problems. We need to address health and fitness broadly across socioeconomic strata and at all stages of life.

Specific responses to Issue areas #5, #7 and #8 are outlined below.

Issue Area #5 – Telehealth and Remote Monitoring Technology

As noted above, in the last 10 years, the increasing availability of mobile technologies has created a new avenue to influence health behaviors. The broad use of smart phones is less than ten years old, yet it has completely changed our ability to both measure behavior and respond quickly to feedback. Mobile phone-based health technologies, known colloquially as mHealth, are changing how individuals interact with health care providers. mHealth creates opportunities for tracking behavior, communicating with health professionals, and even running diagnostic tests outside of hospitals. Devices that measure a number of physiological parameters or behaviors are now becoming commonplace and can be referred to as the general category of "wearables." Wearables can track physical activity, sedentary behavior and sleep, creating a picture of activity and recovery that was previously extremely difficult to measure, and rarely done outside of the laboratory. Wearables are more objective and generate more detailed data than previous research that relied heavily on self-reports, which are subject to recall biases, forgetfulness and attitudes toward physical activity. With more precise measurement of activity, we can begin to make evidence based recommendations for physical activity tailored for individuals of different ages.

In addition to monitoring behavior and health, we need to effectively modify behavior in ways that prevent lifestyle diseases (e.g. diabetes, CHD, and certain types of cancer). In some people tracking itself may change behavior; tracking also leads to unlimited opportunities for providing feedback in personalized and meaningful ways. Of course, the approach is not without concerns. Monitoring entails privacy concerns: physicians monitoring patients may be seen as a nuisance, insurance companies setting rates based on behavior may be objectionable too. Thus, policy makers will likely have a role in regulating the use of mHealth data; this will involve balancing interventions that improve health with privacy concerns.

Some express concern that older people will be unable to adjust and adapt to new technologies, but we view this primarily as a challenge to designers. Seniors have shown a willingness to adopt technologies when they provide real value and when interfaces are well-designed. A prime example is Skype, which has enjoyed significant levels of use by older people as they use it to communicate with family, and in particular grandchildren.

Given the scope of the challenges in changing a wide range of health related behaviors, we will need to motivate a number of small lifestyle changes through a variety of techniques across a wide range of ages. Interventions that integrate classic educational approaches with individualistic approaches, such as mHealth, and population-level environmental approaches that aim to modify an individual's choice set, will likely have the best overall chances of success. We also need to invest in and disseminate cost-effective home based technologies, from fall detection to medication adherence to home-based physician consults.

Technology implementation remains a paradox: while widely scaling technology promises to bring costs down to levels that can benefit people at all socioeconomic levels, current solutions from industry are mainly targeting higher income individuals. In this arena, government can be the catalyst. If clear reimbursement models including cost and functionality targets can be established, the mHealth industry can be unleashed on chronic disease management and the same cost/scale relationships that have resulted in ubiquitous computers and smartphones can lead to health management solutions at levels accessible to the whole population.

Issue Areas #7 and #8 – Patient Health Management and Health Care for Patients living with Chronic Conditions

Among the many important issues associated with multiple chronic conditions is that they greatly complicate how people die. Just a century ago, most people died from acute diseases for which there were few life-saving medical options. In the 20th century, medical and technological advances dramatically changed the course of life, contributing to improved health and dramatic increases in life expectancy. Advances continue today at a remarkable pace, increasing the potential to extend life for months and years, even in the face of life-threatening illness. Many diseases, such as cancer and HIV, previously considered death sentences, can now be successfully managed for years.

Extending life in the face of life-threatening illness comes with the potential for significant trade-offs and risks of prolonging pain and suffering as people approach the end of their lives. People often have options to undergo life-saving treatments that come with considerable risk of reduced quality of life. Once again, placed in historical contexts, these are brand new challenges that raise ethical as well as medical issues. Recognizing that death eventually comes to us all begins to allow conversations about "good deaths" – namely, dying with dignity, with minimal pain, in a setting of one's choosing. Among older people, illness and the loss of independence are feared more than death itself. Several studies have shown that 70 percent of those surveyed say that they want to die in their own homes, but in reality only 32 percent do, with a large preponderance of deaths occurring instead in sterile clinical settings.

There is an insidious irony that prolonged and painful medical care, which patients often fear more than death, comes at enormous financial cost. The cost of care in the last year of life consumes more than a quarter of the Medicare budget and too often depletes family resources along the way. The United States spends twice as much per capita on health care as any other country, and cancer costs alone are expected to rise from $125 billion in 2010 to $173 billion in 2020 largely due to the aging of the population.

One of the many strengths of Stanford University is the wide range of multiple disciplines and the variety of experts who are convened to solve key problems in our society and culture. On April 16-17, 2015, the Stanford Center on Longevity (SCL), under the leadership of Dr. Laura Carstensen (Founding Director of the Stanford Center on Longevity, and Professor of Psychology and the Fairleigh S. Dickinson Jr. Professor in Public Policy at Stanford University), gathered many of the nation's top scientists and thought leaders, representing a broad range of disciplines including family sociology, medicine, ethics, health economics, law, health policy, and psychology, to launch a program of research on the topic of end of life and chronic illness care. Together, the group identified important and unexamined issues about end-of-life practices that, if answered, could inform policies and improve practices surrounding care in the face of life-threatening illness. The meeting focused on the fact that Americans are increasingly talking about end of life issues, and calling for change in how end of life decisions are managed. Yet, it is just as clear that most individuals and families are unsure what they desire at end of life and that many are ill-equipped to make end of life decisions.

Together with a select group of collaborators from the meeting, we have prioritized our research and intervention goals, and have begun the process of seeking funding for three main projects:

1. A "Refining the Questions" project to develop metrics and measures to best meet the needs of patients and families at the end of life;
2. A "What Americans Want at the End of Life" Survey, a nationally representative survey to better understand the beliefs and behaviors of people hear the end of life;
3. A "Close the Gap" Challenge to transdisciplinary scientific research teams to close the remaining gap between end of life wishes and desires and actual outcomes.

Dr. Diana Dooley, California Health and Human Services Secretary, who also attended the launch conference, expressed support for our proposed efforts and offered guidance about aligning our work with the end of life care improvement goal of the State of California's initiative "Let's Get Healthy California."

The Center will also explore the ways in which its work can inform policy research and legislation. For example, U.S. Sens. Mark R. Warner (D-VA) and Johnny Isakson (R-GA) have introduced legislation designed to give people with serious illness the freedom to make more informed choices about their care, and the power to have those choices honored. This legislation, the Care Planning Act of 2015, is an important step in the direction of informed family decision-making.