

Program Impact Report: Oregon's Living Well with Chronic Conditions

Authors

**Dr. Viktor E. Bovbjerg
Ms. Sarah Jane Kingston**

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Summary

This report is the result of an external impact assessment of the Stanford Chronic Disease Self-Management Program (CDSMP), referred to as *Living Well with Chronic Conditions* in Oregon. Living Well is an evidence-based chronic disease self-management program conducted in both English and Spanish (*Tomando Control de su Salud*) throughout the state of Oregon, with an HIV/AIDS-specific program (*Positive Self-Management Program*) also available. The Living Well program has demonstrated both feasibility and popularity by conducting well-received workshops throughout the state. The vast majority of these workshops have been *Living Well*, while *Tomando* and *Positive Self-Management* workshops were increasingly fielded during the past two years. Through December 2009, Living Well programs have enrolled 3,919 participants in 376 workshops, with participation growing from fewer than 100 in 2005 to over 1,300 in both 2008 and 2009.

Based on the best available estimates from scientifically rigorous CDSMP evaluations in other settings, and using Oregon Living Well data from August 2005-December 31, 2009, Living Well is predicted to have resulted in

- 107 quality adjusted life years (QALY) gained
- 557 avoided emergency department (ED) visits, saving \$634,980
- 2,783 avoided hospital days, saving \$6,501,088

In addition, Living Well is likely to have improved participant quality of life through reduced fatigue and increased physical activity, improved emotional and physical well-being, facilitated social functioning, and improved patient-clinician communication.

The goal of the Oregon Living Well program is to make Living Well accessible to all Oregonians with chronic health conditions so they may benefit from the improved health outcomes demonstrated by the original research. The program to date, though successful, has reached approximately 3,900 of 1,566,000 Oregonians living with chronic disease. If Living Well enrolled only 5% (78,300) of eligible Oregonians, its estimated five-year effects could include

- 2,138 quality adjusted life years gained
- 11,119 avoided ED visits, saving \$12,675,660
- 55,593 avoided hospital days, saving \$129,865,248

Living Well has been successful in its statewide implementation, has been well received by participants, and has likely contributed to participants' quality of life while reducing health care costs. To achieve greater impact, Living Well must:

1. identify participant recruitment approaches, workshop venues, and alternate workshop delivery media that promote access to all Oregonians;
2. find a sustainable financial model, one which fully integrates Living Well into Oregon's health reform; and
3. establish an ongoing and comprehensive evaluation.

Expansion of Living Well, as part of local efforts to promote community health and statewide health reform efforts, is likely to help achieve Oregon's goal of improving the lifelong health of Oregonians while containing system-wide costs.

Living Well with Chronic Conditions

The Stanford Chronic Disease Self-Management Program,¹ called Living Well with Chronic Conditions in Oregon (*Living Well*, and related programs including Spanish-language *Tomando Control de su Salud* and *Positive Self-Management Program* for people living with HIV/AIDS), is an evidence-based health promotion program for people living with chronic conditions. The Stanford CDSMP has been recommended to states by the Centers for Disease Control and Prevention (CDC) and the Administration on Aging (AoA). CDSMP programs are widely implemented both in the US and internationally, with translation into 17 languages.²

Living Well workshops are delivered in six weekly sessions of two-and-a-half hours each, primarily in community settings: senior centers, churches, libraries, Area Agencies on Aging, clinics, and hospitals. Participants meet in small groups of 10-15 people, and may have any chronic condition, or multiple conditions. Workshops are facilitated by two trained peer leaders, at least one of whom lives with a chronic medical condition. Living Well complements ongoing medical care by providing participants with the skills needed to manage their conditions, including coordination of medical care and medications. To enhance support, family members are encouraged to attend.³

Subjects covered in Living Well workshops include but are not limited to:

1. Goal setting, problem solving and action planning to achieve self-management goals
2. Techniques to deal with frustration, fatigue, pain, and depression
3. Appropriate exercise for improving strength, flexibility, and endurance
4. Appropriate use of medications
5. Communicating effectively with family, friends, and health professionals
6. Healthy eating
7. How to evaluate new treatments

Statewide implementation

The Oregon Department of Human Services (DHS) – Public Health and Seniors and People with Disabilities Divisions have supported implementation of Living Well in Oregon using a variety of federal grant funds since 2003. DHS provides leader training, technical assistance, and participant books to local organizations that are licensed by Stanford. DHS also coordinates the Oregon Living Well Network, comprised of local program representatives around the state, oriented around workgroups that provide resources and guidance to further the Oregon Living Well Program in its goal of being accessible to all Oregonians with a chronic health



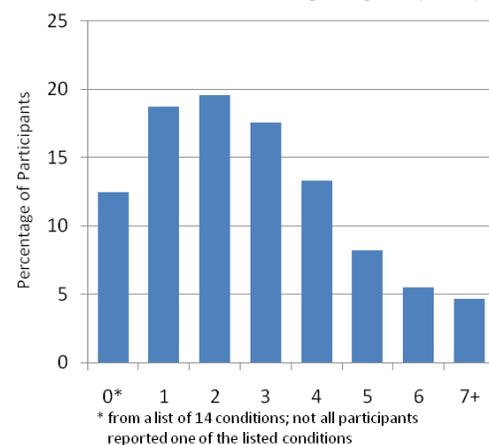
condition. Local organizations offering Living Well in Oregon include hospital systems, local health departments, faith communities, aging services providers, Oregon State University Extension services, and social service agencies.

The number of workshops per year has expanded considerably since 2005, when state-wide data collection was initiated.³ To date, Living Well has conducted 376 workshops: 334 (88.8%) have been *Living Well*, 33 (8.8%) *Tomando*, and 9 (2.4%) *Positive Self-Management* (on which formal data collection began in November 2008). Workshops have been geographically dispersed, having been conducted in 27 of Oregon's 36 counties. There is substantial variation in the number conducted by county, however, with ten counties conducting 10 or more workshops since 2005, and 14 counties conducting five or fewer.

A total of 3,919 participants enrolled in the workshops during 2005-2009, and program effect estimates are based on these participants. Of the 3,919 participants, 3,916 provided individual level data: 3,571 chronic disease participants and 345 support people, most with chronic diseases of their own. Workshop size averaged 10.4 participants, and average participant age was 62 years. Living Well is one of few evidence-based approaches to self-management which is not disease-specific, and is therefore not only efficient to administer, but is uniquely suited to people with multiple conditions. The average number of chronic conditions was 2.7, with approximately 20% reporting four or more chronic health conditions, suggesting that Living Well is attracting an appropriate audience for chronic disease self-management.

The workshops have attracted participants from diverse groups, including 437 participants of Hispanic background (11.2% of participants), roughly the same rate as their representation in the Oregon population, and 118 Native Americans (3.0%), roughly twice the rate as their representation in Oregon. African Americans, however, were underrepresented at 1.3% of participants. Three-fourths of participants (76%) were women. During 2005-2009, approximately 71% of participants who signed up for Living Well completed four or more of the six sessions.

Number of chronic diseases among Living Well participants



Though a statewide participant post-intervention satisfaction survey has not been conducted, most organizations collect some type of feedback from participants completing workshops. The Living Well program in Jackson and Josephine counties has conducted several "Participant Reunions" at which participants were asked to describe how they were using the skills they learned in workshops, and their self-confidence in managing their chronic conditions. While those at the

"I am able to tackle and accomplish projects I thought were undoable!"
- Living Well Participant

reunions may not have been entirely representative, they were nearly unanimous in their positive evaluations. Participants valued learning action planning and problem solving skills and reported greater confidence in their ability to manage their conditions. Of 49 participants in the “reunions,” 20 (41%) reported that “action planning”—making concrete plans to manage chronic conditions—was the most useful activity they learned, while 38 (78%) said their confidence in managing their condition had increased, versus only 2 (4%) who reported their confidence had not increased. Many reported that their physicians had either referred them or were enthusiastic about their participation. One-fifth of Living Well participants reported hearing about the program from a clinician or in a clinical setting,³ and 22 of 49 “reunion” participants (45%) reported that they had discussed Living Well with their physicians. Improved patient-clinician communication may in turn improve both quality of care and patient satisfaction.

“[My doctor] had heard about the program and recommended I attend”
- Living Well Participant

Although the workshop content, leadership, and execution are standardized, Living Well has been implemented across Oregon with variations in time of day, locations, and funding models. The Oregon Living Well program estimated a per participant cost of \$375, based on a 2009 statewide cost survey of Living Well programs. These costs are currently supported in a variety of ways by local organizations, including a mix of grant funding, in kind support, and organizational support. While most workshops have been supported by external funding, 68 workshops (18.1%) required participants to pay an average of \$25, with 25% of those charging \$10 or less, and 20% charging \$40 or more. In some workshops, these fees were paid by participants’ health plans, while in others they were borne out-of-pocket. The vast majority of these workshops (62 of 68 which required payment, 91.1%) were English language programs, and concentrated in five counties (59 of 68, 86.8%).

Living Well Impact to Date

Grants from the CDC and AoA have supported statewide training and technical assistance to implement Living Well with fidelity to the CDSMP model, but have not provided support for comprehensive evaluation. Several well-done evaluations of CDSMP in other participant populations allow estimation of the likely impact of Oregon’s Living Well to date. Most evaluations of CDSMP have reported short-term effects (6-12 months), and studies reported so far have not been large enough to estimate changes in healthcare utilization with high levels of precision. Previous studies have consistently shown improvements among CDSMP participants in health related quality of life and well being: improvements in subjective health status, greater vitality and reduced fatigue, fewer role limitations, improved psychological well-being, increased physical activity, and improved ability to manage chronic conditions (greater disease-specific self-efficacy and improved communication with physicians).⁴ Findings for healthcare utilization have not been as consistent, partly due to the manner in which healthcare utilization results have been reported,

The program adopted by Living Well has strong evidence for improving quality of life, and moderate evidence for healthcare cost savings.

and partly due to the substantial variability typically seen in healthcare utilization. Studies to date have not followed participants in sufficient number or duration to determine utilization effects beyond two years.

We estimated the impact of Living Well by applying findings from similar settings and populations to the participants who have successfully completed Oregon Living Well workshops (i.e. the 71% who attended at least 4 of 6 sessions) during 2005-2009. Since there have been no truly long term studies of Living Well, we assumed that the effects of the program did not last longer than the longest study done to date—2 years.^{5,6} As longer-term outcomes studies are reported from a wider range of locations, revised impact estimates may well paint a somewhat different picture of Living Well effects. (An appendix to this report describes the studies relied upon and details the methodology used to generate the estimates which follow.)

Quality of life, health and functional status, disability, and confidence

It is very likely that Living Well has resulted in quality of life improvements for Oregonians. Studies on individual outcomes as a result of participating in Living Well consistently show improvement in both physical and emotional well-being.⁴ On average, Oregonians in Living Well can expect one additional week of “perfect” health per year more than they might have had without the program (i.e. the time *equivalent* to one week of disease- and limitation-free life, though by definition Living Well participants have one or more chronic diseases at the start of their participation).⁷ If Living Well costs \$375 per participant, the estimated cost for all 3,919 participants is \$1,468,500, for a gain of 5,566 weeks (107 years) of “perfect” health, or \$13,734 per year gained. This figure is substantially more cost effective than other approaches to chronic care management, such as telephone disease management support with nurse care management, which can cost \$30,000 per year gained.⁸

Living Well is also likely to have had important effects on physical and social functioning. Some of the most consistent results from CDSMP evaluations are that participants have increased vigor and energy, improved self-confidence around disease self-management, lower health distress, improved social role functioning, and improved psychological well-being.⁴ For an older participant, Living Well may allow continued independent living. As one participant said, “I’m still walking. I can’t do too much, but I am still trying.” For younger participants, Living Well may allow them to take control of their own care, and relieve some burden from informal caregivers. One participant said, “I go to the doctor and don’t rely on my parents. I’m eating better and making better choices.” When asked on a 0-10 scale about their ability to control their chronic conditions several months after going through Living Well workshops, 38 of 42 responding participants (90%) attending a “Participant Reunion” rated their ability a “7” or better, and only 2 rated themselves at “5” or lower.

“[I] always wanted to do a running race and the [Living Well program] sparked my confidence. I’ve run 2 races. I will run the “Aloha 8 mile Run” even if I have to walk.”
- Living Well Participant

Other evaluations of CDSMP have reported reductions or slowing of disability, fewer social and physical limitations, and improvements in mobility⁴—suggesting that Living Well is highly likely to be improving Oregonians’ ability to live independently, be engaged in their social and community lives, and avoiding placements in care facilities. Unfortunately, none of the metrics used in the studies to date can be mapped onto well-documented predictors of primary (i.e. not following hospitalization) nursing home placement, so it is impossible to estimate the effect of improved functional status on this important personal and healthcare utilization outcome.

Healthcare utilization and costs

Healthcare utilization, particularly for acute care, is very likely to be reduced in Living Well participants who complete at least four of the six workshop sessions. The best estimates, from patient populations in the west coast of the United States demographically similar to Oregon Living Well participants, suggests that participants, on average, reduced emergency department visits from 0.8 to 0.7 visits per year, hospitalizations from 0.4 to 0.3 visits per year, and hospital days from 2.4 to 1.9 days per year.⁵ For the participants who have completed Living Well to date, this translates to 557 fewer emergency department (ED) visits, 557 fewer hospitalizations, and 2,783 fewer hospital days. In 2007, the average cost of hospitalization in Oregon was \$2,336 per day.⁹ Thus, Living Well is estimated to have saved Oregon health plans and Oregonians \$6,501,088 in hospital costs. Similarly, the average cost in 2007 for an ED visit in the western US was \$1,140,¹⁰ yielding an estimated savings of \$634,980 in ED costs among Living Well participants. If program costs are \$1,469,625 (based on \$375 per participant), Living Well is estimated to have saved a net of \$5,666,443, or \$1,446 per participant.

| Estimated Impact of Living Well in Participants to Date | | |
|--|------------------------------|---------------|
| Living Well impact on | Estimated impact | |
| Quality adjusted life years | 107 years gained | |
| Healthcare utilization | | Costs avoided |
| Emergency department visits | 557 avoided ED visits | \$634,980 |
| Hospitalizations | 557 avoided hospitalizations | |
| Hospital days | 2,783 avoided hospital days | \$6,501,088 |

While older individuals generally use healthcare more frequently and incur more healthcare costs, a substantial proportion of chronic conditions and associated healthcare occurs in patients under 65 years of age. Among Living Well participants to date, 57.3% were under 65. This means that the estimated healthcare utilization savings likely benefit both public and private payors in Oregon, as well as federal programs.

Potential Living Well Impact

Through 2009, approximately 3,900 Oregonians have participated in Living Well workshops—roughly 0.3% of the 1,566,000 Oregonians living with chronic disease. If Living

Well enrolled even 5% of eligible Oregonians—78,300 participants— over the next five years as part of comprehensive health reform, its estimated effects would be impressive.

At a cost of \$375 per participant, Living Well would cost an estimated \$29,362,500 for five years, or approximately \$5,872,500 per year. However, these costs would be more than offset by savings in healthcare utilization, averaging \$1,445 per participant.

For this investment in Living Well, participants would gain an additional 2,138 years of “perfect” health, at a cost of \$13,733.63 per quality adjusted life year. At the same time, they would avoid an estimated 11,119 emergency department visits, 11,119 hospital admissions, and 55,593 hospital days. In addition to the healthcare costs avoided, this represents a substantial savings to participants in terms of lost income, both from co-insurance/co-pays and from lost days of work.

It is very likely that participants will experience improvements or prevent further disability, and improvements in physical and mental health described in the previous section; also, the avoidance of hospitalizations and nursing facility stays represents a substantial improvement in quality of life for participants. In turn, these improvements in patient-centered outcomes will have direct but difficult-to-quantify influences on community health and productivity. Finally, Living Well represents a community level resource, and has benefits for local hospitals, clinics, public health departments, and service organizations, which can refer patients and clients to Living Well programs.

Aside from any potential cost savings, Living Well is very likely to improve participants’ quality of life and well-being.

| Potential Impact of Enrolling 5% (78,300) of Eligible Oregonians | | |
|---|---------------------------------|---------------|
| Living Well impact on | Estimated impact | |
| Quality adjusted life years | 2,138 years gained | |
| Healthcare utilization | | Costs avoided |
| Emergency department visits | 11,119 avoided ED visits | \$12,675,660 |
| Hospitalizations | 11,119 avoided hospitalizations | |
| Hospital days | 55,593 avoided hospital days | \$129,865,248 |

Limitations of the Impact Estimates

Though several well-conducted studies have provided the results which underpin this impact report, they are limited in several ways:

1. Most CDSMP follow-up studies have lasted no more than one year, and only one has followed participants for two or more years. Because benefits in the first two years have been reported, we assumed no benefit for participants after two years. It is not yet possible to estimate the longer-term effects of the chronic disease self-management program; however, if the effect of the program extends beyond two years, the cost savings will be *greater* than that estimated for this report. Studies to

date have not examined the crucial question of avoiding long-term care placement or nursing facility use.

2. There are relatively few findings from Oregon’s experience or from experiences in other locations about effectiveness of the chronic disease self-management program in minority populations. The Living Well programs have attracted Hispanic participants, and there are indications that the Tomando program yields short-term benefits.¹¹ The program has not been extensively studied in other traditionally underserved US minority populations, however, and an initial study in an African-American population has found no influence of the program on utilization.¹²
3. The studies used to provide estimates for this report were conducted in “real world” research settings; while they remain the best source for estimates of effect, they may not necessarily reflect the experience of Oregon or other states when implementing the program in non-research settings. In the future, findings combining results from several studies in community settings may provide better estimates of what can be expected in practice; results of thorough evaluation of Oregon’s Living Well outcomes would be the most informative for statewide policy decisions.

Recommendations

Program reach. While the current Living Well program has been successful, it is not without limitations. Most chronic disease self-management programs have difficulty reaching minority populations effectively, and while Living Well appears to have been successful in large measure, greater efforts to recruit and retain participants currently under-represented in Living Well (e.g. African Americans, men) should be implemented. Living Well must reach and retain members of traditionally underserved groups in Oregon, and evaluate the effectiveness of the program in those groups.

While the program has been offered in nearly all Oregon counties, it is not offered with sufficient frequency to be accessible to the majority of Oregonians with chronic diseases. Only 10 counties have offered any version of Living Well more than 10 times since 2005. To reach enough Oregonians to have public health impact, substantially more workshops must be offered. Since Living Well is conducted face-to-face in group settings, it must be offered in geographically diverse sites even within counties—particularly in rural counties. Workshops must also be offered at varying times of day, in order to reach the widest possible audience. Oregon’s population density is roughly half that of the US as a whole, with the vast majority of counties without any metropolitan areas. Therefore, alternatives to “traditional” (in-person, small group) Living Well workshops will also be required to reach all Oregonians. As evidence from online and other distance versions of the chronic disease self-management program become available, they should be demonstrated in Oregon and, if successful, adopted as statewide alternatives for participants unable to travel to a “traditional” on-site workshop.

Similarly, retention of participants, once recruited, is crucial to achieving both individual and public health impact. While 71% retention is comparable or superior to rates in many similar programs,¹³ it nonetheless represents a missed opportunity. In the future,

Living Well staff should attempt to identify predictors of program drop-out, and consider modifications to the program to enhance retention.

Sustainability and integration. If Living Well is to be maintained, and even expanded, a sustainable business model must be developed, which balances needed program resources with achieving the widest possible access to chronic disease self-management programs. The current focus on population health and health reform at the federal and state levels offers an opportunity to build just such a model for support of comprehensive disease management, including chronic disease self-management.

Achieving substantially greater coverage for Living Well will necessitate commensurately greater resources, which evidence to date suggests will be recouped through decreased healthcare utilization. If Living Well is to be fully integrated into health care reform, specifically into the Chronic Care Model^{14,15} and “medical home” concepts central to effective chronic disease control, Living Well must be accepted and actively promoted by clinicians, and patients and clinicians must discuss the goals of the program in the context of ongoing medical management. As part of medical management, Living Well can complement effective medical and pharmaceutical approaches to care. In such a setting, it may be possible that costs associated with Living Well can be weighed against healthcare utilization savings, justifying clinician and staff effort involved in referring patients to Living Well workshops, as well as community organizations’ efforts to ensure availability of community-based workshops for people with chronic conditions.

Evaluation. Living Well staff in both local organizations and at the state level have done an admirable job of collecting implementation data. Living Well participants report leaving the program confident of their improved ability to manage their conditions. The program on which Living Well is based has been extensively evaluated in other settings—the results of the best evaluations were used to generate the estimates in this report. However, there is no substitute for directly measuring the health and healthcare outcomes of the program with Oregon participants. As Living Well is incorporated into Oregon’s health reform agenda, an ongoing, comprehensive evaluation program should be put in place to determine whether Living Well is the best alternative for chronic disease self-management. Such an evaluation should assess important outcomes described in this report (e.g. quality of life, hospital days) as well as outcomes not yet evaluated in other settings (e.g. nursing home placements), and should also evaluate the extent to which Living Well is successfully integrated into patients’ primary care medical homes.

Living Well is the best documented currently available opportunity to achieve the disease self-management goals crucial to comprehensive chronic disease control. In Oregon, disease control is embodied in the “medical home” concept at the center of state health reform efforts, in public health’s efforts to prevent and manage chronic conditions of the population, and in aging and social services’ efforts to maintain the health and independence of clients they serve. If *Living Well with Chronic Conditions* is fully integrated into Oregon’s health and healthcare reform, it will help achieve the goals of improving lifelong health of all Oregonians and promoting more appropriate healthcare utilization.

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About the authors

Viktor E. Bovbjerg, PhD MPH, is Associate Professor of Public Health in the Oregon State University College of Health and Human Sciences. He has conducted evaluations of Medicaid managed care programs, surgical quality improvement networks, and several chronic disease self-management programs.

Sarah Jane Kingston is Deschutes County's Local Program Evaluator for Oregon Project LAUNCH, a child wellness initiative, and a Master of Public Health student in the Department of Public Health at Oregon State University.

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Dr. Viktor E. Bovbjerg
Ms. Sarah Jane Kingston

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Intent

This methods addendum is designed to provide the rationale for the approach, and to describe specific methods used in the report, *Program Impact Report: Oregon's Living Well With Chronic Conditions*. The addendum is intended for those readers of the report who wish greater details about the Living Well data available for the report, decisions made regarding external sources for estimates of effect, or the calculations behind the utilization and cost estimates contained in the report. Although it is structured similarly to a methods section which might appear in a scientific journal article, and has some overlap in intent, the addendum is less technical than those often found in scientific articles. The addendum is not an exhaustive treatment of the potential methods for evaluating Living Well, but rather a description and explanation of the methods used.

Setting

The impact analysis was conducted among Oregon Living Well participants, who took part in the program after the start of data collection in 2005. Participant and program level data were collected at the local level and transferred to state Living Well staff, who aggregated the data and created digital data files. As a complement to the *Living Well with Chronic Conditions: Data Report* published by Living Well staff in January 2010, this analysis was intended to

- summarize the implementation of Living Well to date;
- describe and, where possible, estimate the likely effects of Living Well on quality of life, well-being, and healthcare utilization among participants to date;
- estimate the potential impact of Living Well if extended to a larger group of participants;
- describe the limitations of current estimates of program impact; and
- make recommendations for the future.

Data available

The program staff of Oregon Living Well made three data files available for use: one containing participant data, one containing program data, and one containing program leader data. The participant level data file was used in all calculations describing the participants (e.g. age, mean number of chronic conditions). Participant level data were collected at the local level and transmitted to the state Living Well staff, who created the file. Major elements of the participant level file included demographics (age, race, gender, county of residence, insurance status) and reported chronic conditions. The program level file was used for calculations at the program level (e.g. workshops per year, proportion of workshops requiring payment). Major elements of the program level file included type of program (Living Well, Tomando, Positive Self-Management), location, whether fees were required, recruitment methods, and attendance. Program leader data were not used for this report.

Aggregated data on participants were also available from the report previously published by the Living Well program, *Living Well with Chronic Conditions: Data Report*. Because the participant level data file used to create that report is the same as used in this report, we used some aggregated data (e.g. number of participants per year) from the Data Report.

Participant data were used to calculate descriptive statistics. We used all 3,919 participants (i.e. “primary” participants and attending supporters) to calculate these statistics, both to be consistent with previous Living Well analyses, and because in most cases supporters had at least one chronic condition and would presumably benefit from the program. For the most part, the descriptive estimates used single variables (e.g. age, gender, specific race and ethnicity). To calculate number of chronic conditions, we summed the number of positive responses from a list of 14 chronic conditions which could be selected by participants (arthritis, asthma, cancer, high cholesterol, chronic pulmonary disease, chronic pain, depression, diabetes, fibromyalgia, heart disease, hypertension, HIV/AIDS, multiple sclerosis, and stroke).

We also had access to responses from a small group (n=49) former Living Well participants in southern Oregon, who attended “Participant reunions” at one of the Living well sites. As part of the gatherings, former participants were asked what information from the program they found most useful, how they were currently using that information, whether their confidence in disease management had increased, their level of confidence in managing their conditions, whether they had spoken with clinicians about Living Well, and their interest in leading future Living Well sessions. Estimates based on these data were calculated using the available responses for any given item.

Estimates from external sources

A formal, statewide evaluation of Oregon Living Well has not yet been conducted. Therefore, in order to estimate the likely effect of Living Well on quality of life, well-being, and healthcare utilization and costs, we relied on estimates of effects from other published research using the chronic disease self-management program. While several rigorous studies of CDSMP have been conducted, to date there has not been a quantitative synthesis (e.g. meta-analysis) of the findings from those studies. In addition, there is substantial heterogeneity within the published literature on CDSMP, such that some research articles were inappropriate for use in estimating Living Well effects in Oregon.

We used traditional methods for identifying potential articles for use, including primary searches (e.g. Medline), secondary searches (i.e. identifying articles from the citations of articles already identified), and previous reviews of CDSMP findings (e.g. the National Council on Aging’s *Review of Findings on Chronic Disease Self-Management Program (CDSMP) Outcomes: Physical, Emotional & Health-Related Quality of Life, Healthcare Utilization and Costs*). To be considered a potential source for effect estimates, articles were required to be the result of an intervention (either a randomized clinical trial or a strong pre-post evaluation), and to have provided extensive description of rigorous im-

plementation, evaluation, and analysis methods. The criteria on which articles were evaluated included

- Sound research design, rigorous methods and thorough analysis
 - Description of measures and instrumentation, including documentation of reliability and validity of self-report measures
 - Description of participant recruitment and retention, and reasons for participant withdrawal
 - Appropriateness of statistical analyses
- Adherence to Stanford CDSMP program delivery standards
 - Number of sessions
 - Session content
 - Nature and qualifications of program leaders
- Similarity of study population to Oregon Living Well participants
 - Age
 - Race
 - Sex
 - Access to healthcare, healthcare system
 - Geographic region
 - Number of chronic conditions per participant
- Appropriate, quantified outcomes
 - Length of follow-up for outcomes
 - Estimates for both subjective (e.g. quality of life, health status) and objective (e.g. utilization) outcomes, with estimates of variation (e.g. standard deviations, confidence intervals)
 - Disaggregated healthcare utilization data (e.g. separate estimates for outpatient, inpatient, and emergency department use)
 - Presentation of results from appropriate statistical analyses

We eliminated from consideration those studies which were restricted to populations considerably different from those in Oregon's Living Well (e.g. different age, race, income), or who received care in systems substantially different from those common in Oregon (e.g. United Kingdom and other European countries) and would therefore have different incentives to use or not use healthcare resources. Several studies used combined measures of healthcare utilization (e.g. combined outpatient and ED visits). These were eliminated, because the types of visits are fundamentally different and must be disaggregated. For instance, outpatient visits may remain unchanged or rise with improved quality of chronic disease care (perhaps due to increased participant self-efficacy and patient-physician communication—goals of CDSMP), while ED use should fall with improved disease management. Most studies followed participants for relatively short periods after the program (i.e. four to twelve months). When possible, we sought estimates from programs that had followed participants for at least one year.

Of the available studies, relatively few met even most of the criteria above. Only one provided a well-documented, quantitative estimate of the effect of the program on quality adjusted life years.¹ Because the program was conducted in the United Kingdom, we

were comfortable using their estimates for QALYs, but not comfortable using their estimates for utilization as they are generated from a healthcare system with very different limitations on access to care. Few studies examined utilization sufficiently disaggregated by type of service. The study which came closest to meeting the criteria above for healthcare utilization was conducted predominantly on the west coast of the United States, and study participants were similar to Living Well participants in many respects.²

| Comparison of Living Well participants to study sample ² used to generate utilization estimates | | |
|---|-------------|--------------|
| Characteristic | Living Well | Study sample |
| Mean age (years) | 62 | 62 |
| % female | 76 | 73 |
| % Caucasian | 76 | 83 |
| Mean number of chronic conditions | 2.7 | 2.3 |

The study followed participants for one year in a “real world” (vs. controlled research) setting, and reported separate results for outpatient, inpatient, and emergency department utilization, along with estimates of variation and “statistical significance” for those estimates. The study used a CDSMP intervention that has been demonstrated to have effects on quality of life and utilization up to two years post-intervention.

A consistent finding across CDSMP evaluations has been improvement in health status, quality of life, and physical and emotional well-being.³ These findings have held across health conditions and across populations, and have been estimated using well documented, standardized assessment tools. Because the most common form of reporting such findings is change over time on an assessment score, it is difficult to translate these robust findings into clinically meaningful results. We therefore have reported the areas in which past research has strongly suggested that Living Well is likely to have improved participants’ lives, but have not attempted to quantify or describe the magnitude of the effect.

Calculations of estimates for Living Well

Because we did not have utilization data from Living Well participants, our estimates of effect relied on several important, but reasonable assumptions:

1. *Duration of effect.* Some studies reported significant improvements in quality of life and healthcare utilization up to two years following the intervention, and none followed participants longer than two years. Therefore, we assumed that the effects of Living Well would not be longer than two years post-intervention.
2. *Participation rates.* Living Well staff have estimated that 71% of those who enroll in Living Well complete at least four of the six sessions. Previous studies have found that “completers” differed from non-completers in health status and health behaviors. We therefore “applied” the quality of life improvements and utiliza-

tion/cost reduction estimates to 71% of the total Living Well sample, but used the entire sample when calculating program cost per participant.

3. *Utilization costs.* Because we did not have individual measures of healthcare utilization, we used estimates of the mean utilization costs from roughly the mid-point (2007) of the period during which Living Well data were collected (2005-09). Mean cost of a hospital day in Oregon was obtained from the U.S. Census Bureau's State and Metropolitan Area Data Book, and mean cost of an emergency department visit in the western United States was obtained from the Agency for Healthcare Research and Quality Medical Expenditure Panel Survey.

Given that participation rates were relatively high, and that estimates around mean utilization costs are similar across sources, the most likely source for meaningful variation in the estimates comes from the substantial variation around the utilization estimates, and the assumption of a two-year effect.

To estimate effects, we calculated person-years of effect per participant (i.e. two person years of effect for 71% of the 3,919 Living Well participants). Living Well staff had previously estimated a per participant program cost of \$375, using Oregon Living Well program site data.

Estimated effect of LW to date: Effect calculations

| Year | Enrolled | Completers (enrolled * .71) | Person-years/ completer | Person- years |
|-------|----------|--------------------------------|----------------------------|------------------|
| 2005 | 53 | 38 | 2 | 76 |
| 2006 | 366 | 260 | 2 | 520 |
| 2007 | 816 | 579 | 2 | 1158 |
| 2008 | 1376 | 977 | 2 | 1954 |
| 2009 | 1308 | 929 | 2 | 1858 |
| Total | 3919 | | | 5566 |

- Quality of life effect (from Richardson et al, *J Epidemiol Community Health* 2008; 62: 361-367): 0.020 QALY gain, based on baseline and 6 month survey:
 - 0.020 QALY gain in CDSMP compared to control group, or 1 week/year
 - 1 week/year * 5566 person-years=5566 weeks=107 quality adjusted years gained
 - cost/QALY=\$1,469,625/107=\$13,734.81
- Healthcare utilization effects (based on Lorig et al, *Eff Clin Pract* 2001; 4: 256-62)

| | Baseline (6 months) | Annualized | 12 month reduction | Annual post-CDSMP |
|------------------|---------------------|------------|--------------------|-------------------|
| ED visits | 0.4 | 0.8 | 0.1 | 0.7 |
| Hospitalizations | 0.2 | 0.4 | 0.1 | 0.3 |
| Hospital days | 1.2 | 2.4 | 0.5 | 1.9 |

- ED visits:
 - reduction of 0.1 visit per person-year
 - $0.1 * 5566 \text{ person-years} = 556.6 = 557 \text{ fewer ED visits}$
 - cost/ED visit=\$1,140 (MEPS, 2007)
 - $\$1,140/\text{visit} * 557 \text{ visits} = \$634,980$
- Inpatient visits:
 - reduction of 0.1 visit per person-year
 - $0.1 * 5566 \text{ person-years} = 556.6 = 557 \text{ fewer hospital admissions}$
- Inpatient days:
 - reduction of 0.5 days per person-year
 - $0.5 * 5566 \text{ person-years} = 2783 \text{ fewer hospital days}$
 - Oregon cost/hospital day=\$2,336 (US Census Bureau)
 - $\$2,336/\text{day} * 2783 \text{ days} = \$6,501,088$
- Cost savings:
 - cost=\$375/participant
 - program cost= $\$375 * 3919 = \$1,469,625$
 - gross savings= $\$634,980 + \$6,501,088 = \$7,136,068$
 - net savings= $\$7,136,068 - 1,469,625 = \$5,666,443$
 - savings/participant= $\$5,666,443 / 3919 = \$1445.89 = \$1446/\text{participant}$

Effect calculations for potential effect

- Assumptions
 - 78,300 participants—5% of adult Oregonians with at least one chronic medical condition
 - same participation rates as above: $0.71 * 78,300 = 55,593$
 - same effect size and duration as above: $55,593 * 2 \text{ person-years} = 111,186 \text{ person-years}$
- QoL effect (from Richardson et al, *J Epidemiol Community Health* 2008; 62: 361-367): 0.020 QALY gain, based on baseline and 6 month survey:
 - 0.020 QALY gain in CDSMP compared to control group, or 1 week/year
 - $1 \text{ week/year} * 111,186 \text{ person-years} = 111,186 \text{ weeks} = 2138 \text{ quality adjusted years gained}$
 - cost/QALY= $\$29,362,500 / 2138 = \$13,733.63/\text{QALY}$
- Healthcare utilization effects (based on Lorig et al, *Eff Clin Pract* 2001; 4: 256-62)
 - ED visits:
 - reduction of 0.1 visit per person-year
 - $0.1 * 111,186 \text{ person-years} = 11,119 \text{ fewer ED visits}$
 - cost/ED visit=\$1,140 (MEPS, 2007)
 - $\$1,140/\text{visit} * 11,119 \text{ visits} = \$12,675,660$
 - Inpatient visits:
 - reduction of 0.1 visit per person-year
 - $0.1 * 111,186 \text{ person-years} = 11,119 \text{ fewer hospital admissions}$
 - Inpatient days:
 - reduction of 0.5 days per person-year
 - $0.5 * 111,186 \text{ person-years} = 55,593 \text{ fewer hospital days}$
 - Oregon cost/hospital day=\$2,336 (US Census Bureau)

-
- $\$2,336/\text{day} * 55,593 \text{ days} = \$129,865,248$
 - Cost savings:
 - cost=\$375/participant
 - program cost=\$375*78,300=\$29,362,500
 - gross savings=\$12,675,660+\$129,865,248=\$142,540,908
 - net savings=\$142,540,908-\$29,362,500=\$113,178,408
 - savings/participant=\$113,178,408/78,300=\$1445.89
=\$1445/participant

Limitations of current methods

The limitations of the methods used in this report have been described briefly in the main report, and limitations described here will focus on those with the greatest potential to alter the results estimated in the report.

Living well data. While the data files received from Living Well were comprehensive and complete, we did not have access to primary data with which to verify the accuracy of the data. This is a challenge common to all studies involving “secondary data,” including all studies examining healthcare claims and other administrative data. We also have no direct information on the completeness of the data set—that is, how many Living Well participants declined to complete the information, or whether those providing information differed from those who did not. It is also possible that data were not transmitted on all participants from the local to the state level. Despite this, we have no reason to expect that the number of “missing” participants is large, or that those on whom data were not collected differed in any meaningful way from those on whom data were collected.

Data from the “participant reunions” came from one region in Oregon, and may therefore reflect aspects of Living Well which were specific to that area or the program staff in that area. Again, we have no evidence of such potential differences. It is more likely, but impossible to document in this specific instance, that the participants who chose to attend the reunions were those most favorably disposed toward the program. If that is the case, then the highly favorable evaluations may represent an overestimate of participant enthusiasm for Living Well. The positive evaluations, however, are consistent with those reported in the literature—participants in research settings have also evaluated CDSMP programs positively.

Quality of life estimates. Quality of life is an inherently subjective assessment, and standardizing quality of life to quality adjusted life years is controversial. A quality-adjusted life year (QALY) assesses disease burden by taking into account not only the quantity of life (i.e. being alive or dead) but also the quality of the life lived. A single quality adjusted life year can be interpreted as one year with perfect health. In the case of a person with chronic disease, of course, one QALY is likely to require more than one year of life, since chronic conditions on average reduce perceived health to something less than perfect health. The information that goes into assessing quality of life typically includes health status and some measure of utility (e.g. distress, degree of limitation) for that health status. In a long-term study, both quality of life and longevity contribute to

QALYs. Because there have been no studies to date of CDSMP sufficiently long to have substantial mortality, QALY gains come from improvements in quality of life. The QALY estimate used in this report used standard approaches to calculations, but were conducted in a study sample that differed in some respects from Living Well participants. Until quality of life assessments are conducted with Living Well participants, the QALY estimates presented in this report should be considered preliminary.

Healthcare utilization estimates. There are several potential limitations to the utilization estimates provided in the report. First, utilization estimates depended, as described above, on extrapolation of results from other settings. To the extent that the utilization experience of Living Well participants differs from those in the study sample used, either prior to or as a result of the program, the estimates will be misclassified. Second, the estimates used here were from a relatively small sample, and therefore had considerable variation, even when “statistically significant.” Despite the relatively low “p-values” associated with utilization differences in this study, the variation around those point estimates mean the estimates are not precise enough for strong confidence. Variation in utilization is often substantial in populations with multiple chronic conditions, so it is not surprising that utilization effects have been difficult to document in CDSMP research.

TABLE 3
Changes at 1 Year in Health Status, Health Behaviors, Self-Efficacy, and Health Care Utilization

| VARIABLE | BASELINE MEAN ± SD (n = 489) | 12-MONTH CHANGE MEAN ± SD (n = 489) | P VALUE |
|---|---------------------------------|---|---------|
| Health status* | | | |
| Disability (0–3) | 0.4 ± 0.4 | 0.0 ± 0.3 | 0.77 |
| Health distress (0–5) | 2.3 ± 1.3 | –0.3 ± 1.2 | ≤ 0.001 |
| Social/role activity limitation (0–4) | 2.0 ± 1.1 | –0.2 ± 1.0 | ≤ 0.001 |
| Illness intrusiveness (1–7) | 3.3 ± 1.4 | –0.2 ± 1.2 | ≤ 0.001 |
| Fatigue (1–10) | 5.8 ± 2.5 | –0.3 ± 2.4 | 0.002 |
| Shortness of breath (1–10) | 3.3 ± 3.0 | –0.3 ± 2.5 | 0.003 |
| Pain (1–10) | 5.2 ± 3.0 | –0.3 ± 2.5 | 0.03 |
| Self-rated health (1–5) | 3.3 ± 0.9 | 0.04 ± 0.8 | 0.20 |
| Depression (0–3) | 1.3 ± 0.6 | –0.1 ± 0.5 | ≤ 0.001 |
| Health behaviors | | | |
| Aerobic exercise (min/wk) | 87 ± 94.7 | 13 ± 97.3 | 0.01 |
| Range-of-motion exercise (min/wk) | 35 ± 49.2 | 9 ± 55.8 | ≤ 0.001 |
| Cognitive symptom management (0–3) [†] | 1.3 ± 0.9 | 0.4 ± 0.9 | ≤ 0.001 |
| Communication with physician (0–5) [‡] | 2.9 ± 1.2 | 0.2 ± 1.0 | ≤ 0.001 |
| Self-efficacy (1–10) [‡] | 5.2 ± 2.2 | 0.5 ± 2.4 | ≤ 0.001 |
| Health care utilization[‡] | | | |
| Physician visits (n, past 6 mo) | 5.5 ± 6.0 | –0.4 ± 7.2 | 0.19 |
| Emergency department visits (n, past 6 mo) | 0.4 ± 0.9 | –0.1 ± 1.0 | ≤ 0.05 |
| Hospitalizations (n, past 6 mo) | 0.2 ± 0.6 | –0.1 ± 0.7 | 0.14 |
| Days in hospital (past 6 mo) | 1.2 ± 5.9 | –0.5 ± 7.3 | 0.12 |

*A lower score is better.

†A higher score is better.

‡Participants were asked to report utilization in the 6 months preceding the follow-up survey.

From Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a self-management program on patients with chronic disease. *Eff Clin Pract* 2001; 4: 256-62.²

Third, we assumed that program effects did not extend past the longest follow-up study to date—two years. If program effects last past two years, even with diminished impact, we will have underestimated the effects of Living Well on utilization and costs. It is also possible that effects in Living Well participants diminished before two years, in contrast

to studies to date, in which case we will have overestimated the utilization impact. Only longer term studies, either in other populations or in Living Well participants, will determine whether CDSMP impact lasts beyond two years. Fourth, cost estimates were made on average costs for inpatient and emergency department visits during the time of data collection. Participant level utilization data, either from self-report or from healthcare claims, would provide greater accuracy in estimates of cost and cost savings.

The ideal solution to the challenges above is a comprehensive, statewide evaluation of Living Well using participant-provided information coupled to healthcare utilization data collected both before and after participation, with sufficient follow-up to generate precise effect estimates. For good programmatic and budgetary reasons, such an evaluation has not yet been mounted. As Living Well is incorporated into plans for health reform in Oregon, we strongly recommend obtaining support for such a comprehensive evaluation, so that Oregon's healthcare, public health, and public policy leaders can make decisions about chronic disease self-management based on data and findings specific to Oregon and Oregonians.

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About the authors

Viktor E. Bovbjerg, PhD MPH, is Associate Professor of Public Health in the Oregon State University College of Health and Human Sciences. He has conducted evaluations of Medicaid managed care programs, surgical quality improvement networks, and several chronic disease self-management programs.

Sarah Jane Kingston is Deschutes County's Local Program Evaluator for Oregon Project LAUNCH, a child wellness initiative, and a Master of Public Health student in the Department of Public Health at Oregon State University.