

SORTING THROUGH THE EVIDENCE FOR THE ARTHRITIS SELF-MANAGEMENT PROGRAM AND CHRONIC DISEASE SELF-MANAGEMENT PROGRAM

SUMMARY OF EXPERT PANEL INPUT AND RECOMMENDATIONS



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Sorting Through the Evidence for the Arthritis Self-Management Program and Chronic Disease Self-Management Program

Summary of the Expert Panel Meeting
Seattle, WA
April 29, 2008

Introduction

Macro International Inc., in collaboration with the Arthritis Program within the Arthritis, Epilepsy, and Quality of Life Branch, Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention (CDC), is conducting meta-analyses of the Arthritis Self-Management Program (ASMP) and Chronic Disease Self-Management Program (CDSMP). The primary purposes of these studies are to:

- examine the effectiveness of ASMP and CDSMP through meta-analyses of existing literature, including clinical trials and pre/post-evaluations;
- understand the contextual and implementation factors that may influence effectiveness; and
- generate recommendations for future policy, practice, and research for CDC's Arthritis Program and its national partners to support people with chronic disease.

The Arthritis Program convened a panel of experts to gain insight into the proposed research questions, criteria, and approach of the ASMP and CDSMP meta-analyses. During the meeting, panelists—with a diversity of expertise in arthritis and chronic disease self-management and meta-analysis methodology—provided their unique perspectives on the studies' design and use of these results for future research, policy, and practice.

This report summarizes the key recommendations and points for considerations put forth by the expert panel. CDC will consider these recommendations and issues in refining these meta-analyses.

Meeting Purpose

The goal of this meeting was to gather the diverse opinions and perspectives of experts in the field of arthritis and chronic disease self-management to inform the development and implementation of the meta-analyses of the Arthritis Self-Management Program (ASMP) and the Chronic Disease Self-Management Program (CDSMP). This meeting provided an opportunity for the expert panelists to examine the results of the preliminary abstraction activities and provide input on the proposed structure of these meta-analyses.

Overview of Preliminary Activities

Prior to the meeting, studies published in peer-reviewed journals and other articles were identified through searches of online databases and reference lists of review articles; additional articles and reports were recommended by CDC staff and the author of the ASMP and CDSMP. Macro identified additional citations through previous meta-analyses and systematic reviews. Macro also conducted a preliminary assessment of the available abstracts to narrow the list to those that specifically studied the ASMP and CDSMP, and to identify the broad categories of outcomes related to these programs.

Expert Panel Meeting Process

The panelists were presented with the proposed components of the CDSMP meta-analysis. The facilitator then asked the panelists a series of questions to help refine the components of the meta-analysis design. They were then asked if the same held true for the ASMP meta-analysis. The facilitator used this sequencing for each meta-analysis component—research questions, inclusion and exclusion criteria, outcomes, and implementation and contextual factors. The panelists also examined the list of eligible studies and evaluations identified through the preliminary review of abstracts. The day concluded with discussions on the strengths and limitations of meta-analysis as a methodology, plans for disseminating results, and next steps for the meta-analyses and the expert panel.

Research Questions

Proposed Research Questions

The panelists were presented the following research questions initially proposed for the meta-analyses:

- What impact does the self-management program have on health outcomes and health care utilization?
- For what audiences (or with which populations) is this program most effective?
- How do contextual and implementation factors influence the health status and health care utilization outcomes of this program?
- Are the program benefits maintained over time?

The panelists agreed with the scope of the proposed research questions for the ASMP and CDSMP meta-analyses, but provided recommendations to help improve the clarity and relevance of the questions.

Highlights of Panel Discussion, Recommendations, and Rationales

- Assess the effect of these programs on health outcomes and health care utilization separately.
Rationale: Distinguishing between the two will provide greater insight into the programmatic effect on health outcomes and health care utilization.
- Specify the timeframe for maintenance of program benefits.
Rationale: The majority of literature reports outcome measures for up to 6 months. Panelists recommended a timeframe of 4–6 months.
- Add a research question on the similarities and differences in arthritis outcomes between ASMP and CDSMP.
Rationale: It is important to know about the similarities and differences in arthritis outcomes (or effectiveness) between ASMP and CDSMP. This information will help agencies serving people with arthritis determine which program to adopt.

Other Considerations

Panelists also provided the following as consideration for future studies, since it might not be within the scope of these meta-analyses:

- What is the effect of these programs on community-level (versus individual-level) outcomes?
 - The answer to this question would help determine if these programs should be considered a medical or public health intervention. This type of focus could help determine if there is a “tipping point,” or degree of reach, that influences outcomes and yields sufficient community-level benefits.
- Panelists were interested in learning more about organizations’ selection and adoption criteria, implementation factors, and mechanisms for change for each of these programs.

Inclusion and Exclusion Criteria

Proposed Criteria

The panelists were presented the following inclusion criteria initially proposed for the meta-analyses:

- Intervention is specifically ASMP or CDSMP
- Study or evaluation is available in English
- Study or evaluation reports at least one outcome measure
 - Effect size is available or can be derived
 - Outcomes are from a controlled trial or evaluation with pre-/post-data
- Language of implementation (English only versus other languages)

Panelists provided feedback on the proposed inclusion criteria and recommended additional criteria for exclusion.

Highlights of Panel Discussion, Recommendations, and Rationales

- Include all delivery modes of ASMP and CDSMP, but conduct sensitivity analyses to see if data on different modes can be combined.

Rationale: The focus of these meta-analyses is program effectiveness. Although the mode of delivery is different, the program is, in essence, the same.

- Include studies conducted in the United States, United Kingdom, Australia, Canada, New Zealand, and any other English-speaking countries, regardless of the language of implementation.

Rationale: Most, if not all, English-speaking countries share a culture similar to that of the United States. Although the language of implementation in these countries may be different, the participants living in that country are part of the broader, Western culture. Including other countries would introduce too much cultural and translation variability.

- Have exclusion criteria. The panelists proposed the following criteria:
 - Intervention was implemented in combination with another intervention.
 - The intervention implementation did not meet the following specifications of implementation:
 - Intervention was not implemented in the prescribed timeframe and frequency (2–2.5 hours, weekly, for 6 weeks)
 - New content was introduced
 - Instructors did not complete the requisite 18–24 hours of ASMP or CDSMP training
 - Instructors did not use the program manual provided at the training
 - Participants did not have access to the ASMP or CDSMP course book

Other Considerations

- Consider the different versions of ASMP and CDSMP. One option is to identify the point when the most substantial changes occurred. Another option is to limit the meta-analyses to implementation of the programs to the past 5 years.
- Include both evaluation studies and research studies. The inclusion of different methods will limit truncation of populations, increase the likelihood of capturing implementation factors, and help highlight the differences between studies. As one panelist described it, randomized controlled trials evaluate efficacy, while pre-/post-studies uncover implementation issues.
- There are complex factors such as health care systems, language barriers, cultural differences, and health disparities associated with exploring ASMP- and CDSMP-focused research conducted outside of the United States. Most foreign health care systems have a different structure than that in the United States, which may indirectly affect some outcomes.
- Program participants in English-speaking countries may vary in ethnic and cultural backgrounds, which raises several key questions that may not be within the scope of these meta-analyses.
 - Does the program work cross-culturally?
 - Do the outcome measures differ cross-culturally?
 - How do cultural differences affect outcomes (i.e., some cultures interpret pain differently)?
- Consider the enrollment size and completion rates of research studies and evaluations.

Outcomes

The panelists were presented with a list of outcomes identified through the preliminary review of abstracts and proposed additional outcomes. Panelists prioritized the following outcomes as most important for assessing the effectiveness of the interventions. The full list of outcomes and the number of votes for each is listed in Appendix A.

Priority Outcomes

- Health status outcomes:
 - Energy/fatigue
 - Functional disability
 - Social role/activity limitations
 - Self-rated health

- Psychological status outcomes:
 - Self-efficacy/self-confidence
 - Depression
- Behavior change outcomes:
 - Exercise
 - Self-care behaviors
 - Communication skills
- Health care utilization outcomes:
 - Number of emergency room visits

Highlights of Panel Discussion, Recommendations, and Rationale

- Clinical outcomes such as blood pressure, glycated hemoglobin (A1c), and others are also worth examining for the CDSMP meta-analysis.
- The following outcomes should be included specifically in the ASMP meta-analysis:
 - Pain
 - Anxiety
 - Change in medication use
 - Number of physician visits
 - Communication with physician

Other Considerations

- *Self-care behavior* should be operationally defined.
 - Rationale:* Some panelists found prioritization difficult because they were not sure of what *self-care behavior* meant. Some of the listed outcomes may be subsumed under self-care behavior (e.g., adherence to medications, communications, physical activity, sleep).
- The coverage of certain issues (e.g., pain) may heighten awareness of that issue, which can influence the reporting of outcomes.
- Participation rates are important in understanding the outcomes measured. Some individuals do not complete the entire intervention, or only sign up at the beginning and come back at the end.
- Although only 1 health care utilization outcome ranked among the top 10 priority outcomes, these outcomes may have a significant effect on policy decision making, particularly for the publicly funded health care systems.
 - Private insurers no longer focus on the cost-savings of programs, but on quality of care and patients' satisfaction with services received. However, public insurers funding such programs are still interested in outcome of cost-savings.

Literature Review

After reviewing the search strategies and identified citations, the panelists suggested additional search methods to help increase the number of studies identified:

- Search cited articles
- Include key phrase, *Expert Patient Programme*, in the search strategy
- Perform Google scholar search
- Search recommended Web sites and databases (e.g., Administration on Aging, Chronic Disease Directors Web site, Healthcare Quality Improvement database)

Meta-Analysis

Panelists were asked about other strengths and limitations of meta-analysis as a methodology and possible strategies to minimize the limitations. The panel members' discussion is summarized below.

- The programs' effectiveness has implications for translatability, generalizability, and external validity. These meta-analyses should look at the studies broadly and focus on populations.
- There may be less heterogeneity among ASMP participants than among CDSMP participants.
 - CDSMP targets those with one or more chronic diseases, while the primary focus of ASMP is improving health outcomes for patients with arthritis.
- The effect size of randomized clinical trials versus nonrandomized clinical trials versus uncontrolled studies should be examined.
- There may be a floor effect in meta-analysis due to the heterogeneity of populations. Since different populations may experience different changes in outcomes, the process of meta-analyses may minimize these effect sizes. For example, one will not find effects of reducing depression if those enrolled were not initially depressed.
- Generalizing findings is contingent upon participant selection for the studies and evaluations. The effectiveness of these programs cannot be appropriately generalized to populations that were not included in the clinical trials or evaluation studies.
 - Caution will be required when making recommendations or policy decisions regarding these programs—if the effectiveness of ASMP or CDSMP has not been studied or evaluated in a certain population, the recommendation or policy may be inadequate.
- The CDSMP meta-analysis should include all disease conditions included in CDSMP intervention studies since most studies do not report outcome measures by disease on the individual level. To the extent possible, the type of disease should be factored into the analysis.
- Populate the evidence table to determine which variables can be included in the meta-analyses.
- An early step of the meta-analyses should be to conduct sensitivity analyses to determine if certain variables can be combined (i.e., can results by different modes of program delivery be combined).
- Studies may need to be weighed by the number of people enrolled or completing the program.

Implementation and Contextual Factors

The panelists were presented with a list of implementation and contextual factors identified through the preliminary review of abstracts and proposed additional attributes for analysis. Panelists prioritized the following as variables to help in understanding the contextual and implementation factors. The full list of implementation and contextual factors and the number of votes for each is listed in Appendix B.

Priority Factors

- Program fidelity
- Recruitment/enrollment strategies (e.g., self-selected versus directed, face-to-face versus mass media)
- Participant education level
- Leader characteristics (e.g., peer versus health care provider)
- Cultural sensitivity/leader match
- Paid versus not paid (referring both to recruitment of participants and instructors)
- Patient conditions
- Setting of intervention (e.g., urban versus rural, community versus health care organization)
- Participant/group demographics

Highlights of Panel Discussion, Recommendations, and Rationale

- If possible, capture the cultural adaptations of the intervention or the changes that reflect cultural appropriateness.
- Consider accounting for disability in all age groups.
- Note that group environment and cohesion is another qualitative factor that may influence program effectiveness.
- Contact the researcher or program implementer to identify implementation and contextual factors not described in the article or evaluation report.

Rationale: This information can help shape future implementation of the programs.

Creating a searchable database would be valuable to program implementers and researchers.

Creating a searchable database will help populate the evidence table, which, in turn, will provide data to stratify by high and low performers.

- Variables of interest include but are not limited to participant characteristics, recruitment, training, implementation, cultural adaptations, organization setting, payments and reimbursements.

Other Considerations

- Qualitative descriptions with respect to differences in study design, populations, staff training, type of intervention delivery, etc., should be reviewed and included as part of the analysis. Variables not eligible for meta-analysis can be described qualitatively.
- Another approach is to stratify high and low performers by outcomes and then examine the implementation and contextual factors

Implications/Dissemination

CDC staff presented the preliminary discussion on the dissemination plan for the results of these studies, including possible audiences and means for communicating these results. These discussion points were as follows:

Proposed Potential Audiences

- Federal Government (for policy considerations)
 - CDC
 - Administration on Aging
 - National Institutes of Health
 - Medicaid/Medicare
- National partners
 - Arthritis Foundation
 - National Council on Aging
- Health care providers
- Researchers

Proposed Modes of Dissemination

- CDC report
- Presentations at professional conferences
- Publication in peer-reviewed journals

Highlights of Panel Discussion and Recommendations

- Add the following potential stakeholders to the dissemination list:
 - State/local governments
 - Payers (e.g., health insurance companies)
 - Philanthropic organizations (e.g., PEW Charitable Trust, the Kaiser Family Foundation, Robert Wood Johnson Foundation)
 - Primary care–based associations (e.g., American Association of Family Practitioners, American Geriatrics Society) that are driving the chronic care agenda
 - Participants—reach through major organizations, such as AARP
 - Teachers of health professionals at academic institutions
 - Physical therapists and fitness instructors
- Add the following products:
 - A common slide set (see Commonwealth Fund’s slideshow and Web site for an example)
 - Congressional briefings

- Add the following modes of dissemination:
 - Web-conference software (e.g., WebX)
 - Peer-reviewed journals—focus on abstracts and executive summaries
 - Mass media—study shows potential for media interest
 - Other nontraditional means

Other Considerations

- Policy implications should also remain at the forefront when thinking about distributing the results of the meta-analyses. Policymakers will focus heavily on the results of the meta-analyses and not on the methodology.
- The final products should demonstrate the benefits of the programs to the participants and expose decision makers to the programs.
- The key piece to disseminate is the abstract/executive summary, since policymakers and other stakeholders may not read the entire meta-analysis reports or full articles.

Next Steps

The meeting concluded with a summary of the next steps for CDC and Macro. The panelists will be consulted toward the conclusion of the meta-analyses to generate recommendations for implications of the results and for the dissemination of findings.

Sorting Through the Evidence for the Arthritis Self-Management Program and Chronic Disease Self-Management Program

Summary of Expert Panelist Interviews
(An Addendum to the Summary of the Expert Panel Meeting)

Introduction

Two individuals, who were unable to attend the in-person expert panel meeting, were invited to contribute their expertise and insight via interviews. This supplemental document provides a summary of the interviewees' thoughts and comments on the Arthritis Self-Management Program (ASMP) and Chronic Disease Self-Management Program (CDSMP) meta-analyses.

Interview Data

The subject matter experts were provided with the proposed research questions and inclusion criteria before the interview. The lists of outcomes and implementation and contextual factors generated at the expert panel meeting were also provided in advance.

Proposed Research Questions

Interview respondents agreed with the overall focus of the research questions and that it is important to examine the contextual factors related to effectiveness.

Recommendations and Rationale

- Identify the primary outcomes prior to conducting the meta-analyses.
Rationale: Determining the outcomes for analysis post hoc will diminish the credibility of the meta-analyses. The analyses should not be based on the data available, but on hypotheses.
- One respondent suggested that questions related to implementation and contextual factors should only be asked after an intervention is deemed effective. The respondent also noted that hypotheses related to this question be determined a priori to establish credibility.

Considerations

- The effect on health care utilization will be minimal to none in the United Kingdom and other countries with similar health care systems.
- The results of the CDSMP meta-analysis may inform health care policy and practices in the United Kingdom.
 - Unlike ASMP, CDSMP was adopted in the United Kingdom before there was research on the program. There has been a backlash because they are not getting the same level of health outcomes as in the original efficacy studies.

Inclusion and Exclusion Criteria

Recommendations and Rationales

- For ASMP, change inclusion criterion to “The study or evaluation includes at least one outcome measure of pain or function.”

Rationale: Pain and function are the primary health outcomes for ASMP.

- Stratify data for the various study designs—randomized control trials, nonrandomized control trials, noncontrolled trials, and pre- and post-test evaluations.

Rationale: Evaluation studies do not control for variables that may confound the results.

Considerations

- Pre- and post-test evaluations, nonrandomized control trials, and noncontrolled trials are unlikely to have the same level of rigor as randomized controlled trials.
- Be cautious when combining study types and the different modes of delivery.
 - One respondent noted that combining the data is acceptable if the sensitivity analysis yields similar effect sizes for the different study types and different modes of delivery.
 - The other respondent indicated that sensitivity analysis is not a strong enough analysis to determine if data from different study types or different modes of delivery should be combined.
- Combining data from programs implemented in English versus other languages (both in native English-speaking countries) may be debated.
 - In past studies, questions have been raised about the cultural changes to accommodate those who attend a course in English versus those who attend a course in another language.
 - Members of minority populations who attend a course in English may be more acculturated than those who attend a course in their native language.

Outcomes

Respondents discussed several points for consideration regarding the meta-analyses.

Considerations

- For the ASMP meta-analysis, one respondent recommended pain and function as the primary outcomes, and that health care utilization outcomes be secondary.
- Reference the article by Paul Shekelle for a list of CDSMP outcomes to examine.
- One respondent doubted if clinical outcomes fit with the essence of these programs.
- Health care utilization outcomes are not a priority for the United Kingdom because most health care services are free, and visits to hospital-based consultants are required each year to maintain benefits.

Implementation and Contextual Factors

Considerations

For both ASMP and CDSMP meta-analyses:

- Focus on implementation and contextual factors as covariants in a meta-regression only after interventions are deemed effective.
- Definitions of these factors are needed but may be difficult to discern from the research.
- Cultural factors are more important than urban/rural classifications.
- The issue of acculturation is important regarding language of delivery.

For ASMP-specific meta-analysis

- Review the Warsi article for the most pertinent implementation and contextual factors. The article lists factors that were examined post hoc using regression analysis; however, the findings were not very strong.

Meta-Analysis

Respondents discussed the limitations of meta-analysis and, whenever possible, provided strategies to address or minimize the limitations.

- Combining different types of interventions can decrease credibility.
 - Focusing on ASMP and CDSMP exclusively and separately will negate this issue.
- Meta-analyses lack the qualitative context of what is going on with people. What individuals have to say about a program is just as important as the results. The qualitative data is of interest to participants—it can give them “renewed hope or purpose.”
 - Integrate qualitative data into the discussion of quantitative data to explain some of the context.
- Meta-analyses do not always include long-term studies. Often, long-term studies do not measure all outcomes, such as managing depression without medication.
 - Pre-/post-test studies might address the lack of long-term studies and provide some insight into longitudinal outcomes.

Implications and Dissemination

Additional audiences for findings of meta-analyses

- World Health Organization
- United Nations
- Governments of English-speaking countries
 - One respondent noted that ASMP and CDSMP are simple interventions that can be implemented in third-world countries.

Additional mechanisms or modes of dissemination of findings

- CDC Web site
- Patient conferences

Citations

Prior to the interview, respondents were sent a list of citations identified through Macro's searches of online databases and reference lists of review articles and as recommended by CDC staff and the author of the ASMP and the CDSMP.

At the conclusion of the interview, respondents were asked to e-mail or send citations for studies or formal evaluations that may be pertinent to these meta-analyses.

Appendix A: Arthritis and Chronic Disease Outcomes

The table below lists the outcomes identified through the preliminary abstract review for ASMP and CDSMP and outcomes recommended by panel members. Panelists voted on the 10 most important outcomes for assessing the effectiveness of the interventions.

Outcome	Number of Votes	Notes/Comments
Knowledge/Attitudes		
Attitudes toward chronic disease self-management	1	
Knowledge of disease/condition	0	
Health Status		
Health status outcome(s) not defined in abstract		
<i>Self-reported outcomes</i>		
Functional disability	10	
Energy/fatigue	9	
Social role/activity limitations	7	
Self-rated health	5	
Pain	5	Important outcome for ASMP
Level of physical activity	4	
Health distress	2	
General health	1	
Shortness of breath	0	
Global severity	0	
Muscle strength	0	
Tender joints	0	
<i>Clinical indicators of health status</i>		
Systolic and diastolic blood pressure	2	Potential outcome for CDSMP
Body mass index	0	
Peak flow	0	
Weight	0	
Erythrocyte sedimentation rate (ESR)	0	
Glycated hemoglobin (A1c) levels	0	Potential outcome for CDSMP
Blood glucose levels	0	
Cholesterol	0	
Psychological Status		
Self-efficacy/self-confidence	10	
Depression	10	
Quality of life	2	
Helplessness	1	
Vitality	1	
Anxiety	1	Potential outcome for ASMP
Mood	1	More specifically, <i>positive mood</i>

Outcome	Number of Votes	Notes/Comments
Reinterpreting pain/ ignoring sensations	0	
Psychological well-being	0	
Locus of control	0	
Perceived autonomy	0	
Social support	0	
Psychosocial well-being	0	
Perceptions of impact and interference of arthritis/positive–negative effect	0	
Role function	0	
Disease acceptance	0	
Mental health	0	
Fear	0	
Behavior Change		
Exercise	10	
Self-care behaviors	8	
Communication skills	6	
Cognitive symptom management	5	
Relaxation techniques	1	
Coping strategies	1	
Stretching	0	
Range of motion	0	
Change in medication use	0	Include outcome for ASMP
Diet, food intake	0	
Compliance with medication	0	
Health Care Utilization	1	
Number of emergency room visits	6	
Number of hospitalizations in past 6 months	3	
Number of physician visits	1	Include outcome for ASMP
Number of nights spent in hospital in past 6 months	1	
Days missed work or confined to home	1	
Communication with physicians	0	Include outcome for ASMP

Appendix B: Implementation and Contextual Factors

The table below lists the implementation and contextual factors identified through the preliminary abstract review for ASMP and CDSMP and additional factors recommended by panel members. Panelists voted on the seven most important implementation and contextual factors for assessing the effectiveness of the interventions. One subject matter expert did not select any factors.

Implementation/Contextual Factor	Number of Votes
Program Characteristics	
Fidelity	7
Accessibility	2
Sponsorship (e.g., sponsoring agency)	1
Incentive	1
Cultural adaptation	1
Language in which the program was implemented	
Research study vs. community-based program	
Recruitment Factors	
Recruitment/enrollment strategies (e.g., self-selected vs. directed, face-to-face vs. mass media)	7
Referral source (e.g., patient provider, agency, testimonial)	1
Agency recruitment vs. community recruitment (otherwise known as mediating agency or constituency agency)	
Peer-to-peer recruitment of new leaders	
Clinician-directed vs. self-directed	
Instructor Characteristics	
Leader characteristics (e.g., peer, health care provider)	4
Cultural sensitivity/leader match	4
Paid vs. not paid (referring both to recruitment of participants and instructor)	3
Lay instructor vs. professional staff	1
Duration of leader training	1
Participant Characteristics	
Education level	4
Patient conditions	4
Demographics of patients/group	3
Age	2
Live alone vs. with others	2
Degree to which participants volunteer	1
Health care	1
Type of disease/condition	
Employment (may be valuable from a policy standpoint)	
Days missed from work	
Marital status	

Implementation/Contextual Factor	Number of Votes
ZIP code	
Income	
Disease diagnosis (physician-confirmed or self-report)	
Disability	
Gender	
Setting	
Setting of intervention	7
Workshop group environment (i.e., social support of group)	3
Urban vs. rural	1
Country in which the program was implemented	
Implemented in English-speaking country	
Community (sponsoring agency) vs. health services	
Poverty (characteristics of community)	
Exposure to Intervention	
Attendance	2
Participant participation	1