Steps to Healthier Living™

Evidence-Based Self-Management Programs

ADMINISTRATIVE/ IMPLEMENTATION MANUAL

SMRC
Self-Management
Resource Center

Steps to Healthier Living™

Evidence-Based Self-Management Programs

ADMINISTRATION/ IMPLEMENTATION MANUAL

This manual may be used to guide administration and implementation for any SMRC Self-Management Program

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SMRC Self-Management Resource Center

REQUIRED

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Table of Contents

Page

I. Program Description 1
- SMRC Self-Management Programs 1
- Does the Program replace existing programs and treatments? 2
- What makes these programs different? 2
- How do we convince health professionals to trust the program? 2

II. What is Needed for Implementation 4
- A Consideration Before Implementation 4
- Program Coordinator 4
- Master Trainers 5
- T-Trainers 7
- Leaders 7

III. Leaders 8
- Selecting Leaders 8
- Leader Recruitment 10
- How are Leaders trained? 11
- When is someone really a Leader? 12
- Something to Think about BEFORE Training 13
- What is needed for training? 13
- How are Leaders monitored? 15
- Are Leaders paid? 16
- How to Retain Leaders 17
- How do Leaders Retain their Status as Leaders 18

IV. Recruiting Participants 19
- Recruiting Systems 19
  - Time 19
  - Data Systems 19
- Recruiting Tools 20
  - Publicity Sources Database 20
  - Potential Participants Database 20
  - Healthy Professionals 21

V. Scheduling 23
- Timing of Workshops 23
  - Time of Day/Day of Week 23
  - Time of Year 23

Page

V. Scheduling, *continued*
Leader Availability 24

VI. Finding Participants 26
Designing Your Own Materials 26
Be Innovative 27
Some Rules of Thumb 28

VII. Professional Backup 29
Someone to Answer Specific Medical Questions 29
Someone to Call in an Emergency 29
What do we do about an emergency during a workshop? 29
Developing a Crisis Protocol 30

VIII. Community Sites 31

IX. Materials for Program Participants 33
How do you assure that participants have all needed materials? 34

X. Program License 35

XI. Working with Different Ethnic and Cultural Groups 36

XII. Evaluation 39
First, let's talk about what not to do 39
Reach 39
Effectiveness 40
Adoption 40
Implementation 41
Maintenance 41

XIII. Cost and Sustainability 42
How to sustain a program 43

XIV. What if I have more questions? 44

Appendix I: History of SMRC Self-Management Programs ..... I: 1
The Arthritis Self-Management Years ..... I: 1
The Chronic Disease Self-Management Years ..... I: 4
The Positive Self-Management (HIV) Years ..... I: 7
The Chronic Pain Self-Management Years ..... I: 7
The Diabetes Self-Management Years ..... I: 8

Page

Appendix I: History of the SMRC Self-Management Programs, *continued*
The Building Better Caregivers Years ..... I: 8
The Cancer Thriving and Surviving Years ..... I: 9

Appendix II: Participants' Leader Evaluation Form ..... II: 1
How to Use These Forms to Evaluate Leaders ..... II: 1
Sample Leader Evaluation Form ..... II: 3

I. Program Description

The SMRC Self-Management Programs (Including *Cancer Thriving and Surviving* and *Building Better Caregivers*)

The Self-Management Resource Center's (SMRC) programs are workshops given two and a half hours, once a week, for six weeks, in community settings such as community centers, senior centers, recreation centers, churches, libraries, clinics, and hospitals. The programs were developed for people with chronic health problems and their significant others (spouses, close friends, close relatives) or for family caregivers of people with memory loss. A description of each of the workshops can be found on our website (www.selfmanagementresource.com). A history of all of our programs can be found in Appendix I of this manual. Two trained Leaders facilitate workshops, one or both of whom are non-health professionals (peers). It is best if both Leaders have the condition of the workshop focus, i.e., pain, diabetes, are cancer survivors, etc. **Please note that the programs are written to be given in 2.5 hour time blocks, and these blocks cannot be shortened or divided.**

Besides condition-specific information, all workshops have some common elements. These include: action-planning, decision-making, and problems-solving. All workshops are designed to be self-tailoring. This means that different participants will be working on different behavior changes and problems, depending on their own needs and preferences.

Trained Leaders always follow a scripted *Leader's Manual*. The workshop developers have scripted every minute of the workshop for content as well as the interactions of the Leaders with the workshop participants. Leaders must follow the manual and not add, change or delete material or activities. They can and should use their own words while still following the script in order to make it relevant and culturally appropriate for their community, and not just read what is written verbatim. If anyone wants changes, they should send suggestions in writing to SMRC@selfmanagementresource.com.

Sometimes there are special reasons to change the program in small ways. Before doing this, however, email SMRC for permission (SMRC@selfmanagementresource.com). For general suggestions for changes in the next revisions, contact SMRC at the same email address. These are considered when the workshops are updated (about every 6 years).

It is the process, or how the workshop is facilitated, that makes it effective. Workshops are highly participative, where mutual support and success build the participants' confidence in their ability to manage their health and maintain active and fulfilling lives.

Do the programs replace existing programs and treatments?

The SMRC programs will not conflict with existing programs or treatment. They are designed to enhance regular treatment and disease-specific education such as Better Breathers, cardiac rehabilitation, or diabetes instruction. In addition, many people have more than one chronic condition. The CDSMP was specifically designed for these people.

What makes these programs different?

All of the programs are evidence-based. This means that they have been evaluated in scientific trials, the results have been published in peer-reviewed journals and the programs have all the materials, including this manual, that make it possible to offer the program at sites throughout the world. Many of the programs have also been named as meeting the criteria as evidence based-programs for U.S. federal funding. The diabetes programs meet all the American Diabetes Association (ADA) standards and many organizations are using it as part of recognized diabetes programs that can receive Medicare reimbursement.

You can find research articles, other publications about the programs and articles about cost and estimated savings in Appendix I and at our website in the "Resources" section.

How do we convince health professionals to trust the program?

- The easiest way to convince health professionals is to let them sit in on one or two sessions of a workshop. Before doing this, however, the participants in the workshop must consent to allowing non- participants to observe. This is necessary to respect the privacy of the participants and to maintain group identity.

- Encourage workshop participants to talk about what they learned in the program with their healthcare providers.

- Many health professionals like evidence, so giving them the abstracts of the key program research articles is useful. Health professionals usually to do not want to read long articles but you can have these available if they want to see them.

- Have trusted health professionals talk about the program to their peers. Health professionals tend to trust their colleagues. Be sure the spokesperson is someone that is mainstream and trusted, not the new fresh kid on the block or the one who always has crazy ideas.

- Make it very easy for health professionals to access workshop information. Today this often means having a website that lists times and places for your workshops as well as an easy way for people to register and a phone number (answered by a real person) to call for more information.

II. What is needed for implementation?

A Consideration before Implementation

While the SMRC programs are relatively low cost, they are not free of cost. If an organization intends to support a program coordinator and Leaders, as well as materials, it must be sure that it has enough long-term funding to cover the costs. In addition, the program must fit with the mission of the agency. While the exact cost of the program varies from agency to agency, it should be in the ballpark of $300 U.S. dollars per participant. This includes everything; training, materials, supervision, advertising, registration, etc. Thus, if you have a grant for $50,000, you should be able to serve about 160 people.

All of the following are needed for program implementation.

- Program license from SMRC
- Program Coordinator
- Master Trainers certified and in good standing (you may be able to borrow these from other agencies)
- Trained and active Leaders
- Systematic participant recruiting (marketing) effort
- Professional backup
- Crisis protocol
- Community sites
- Program materials
- Quality assurance/ fidelity strategies (see section XII, Evaluation)

Program Coordinator

Every organization needs someone who is responsible for the program. This person, the Program Coordinator or Administrator, is sometimes a Master Trainer. The Program Coordinator recruits Leaders, supervises Leaders, arranges for workshop sites, maintains program fidelity and may conduct program evaluation. This is also the person that Leaders turn to in an emergency. Depending on how many workshops your agency offers each year, this can be anything from a 25% time position to a full time position or more. This should **not** be an add-on for an already busy person. It needs to part of a job description with specific time allocations. **Over the years we have found that agencies with such a person tend to succeed and those without tend to have problems.**

Master Trainers

Master Trainers are responsible for training Leaders. Not every organization needs Master Trainers. In fact, if you are planning on training Leaders less than twice a year you are probably better off teaming with a nearby licensed organization and training your Leaders together. All Leaders must be trained by Master Trainers. You will need two (2) Master Trainers in order to hold a Leader training. These trainers may work for your agency or 1,500 Master Trainers in the US. A list of all currently certified Master Trainers is on the SMRC website's private Trainer section. If you need help finding Master Trainers, please look at our website (www.selfmanagementresource.com) or call 1-650-242-8040.

All Master Trainers are certified. To become certified, a person must complete a 4.5 day master training (or a cross-training, if eligible) conducted by two certified T-Trainers. These can take place at Stanford University or can be arranged through SMRC to take place anywhere in the world. In Canada, the Training Coordinating Center is at the University of Victoria in British Columbia headed by Dr. Patrick McGowan (pmcgowan@uvic.ca), in England at Talking Health (www.talkinghealth.org; Jean Thompson at jean@talkinghealthtakingaction.org). German and French-speaking countries should contact Jeorg Haslbeck (Joerg.Haslbeck@careum.ch). For Chinese, contact Peter Poon (peter.poon@rehabsociety.org.hk). For Spain contact Fede de Gispert Boix (fede@vively.es).

Following training, recommended Master Trainers must lead two complete six-week workshops. These workshops can be co-led with a certified Leader (who could also be a potential Master Trainer), a certified Master Trainer, or a certified T-Trainer. For full details about training and requirement to maintain certification see the SMRC self-management programs *Fidelity Manual*.

Once Master Trainers meet these requirements, they submit the Master Trainer Agreement and Certification Form to SMRC and are sent a letter of certification. At this time, their name also appears on the SMRC website. Any active Master Trainer can access the private part of the website.

Over the years, we have learned that if an agency wants to have their own Master Trainers, it is best if more than two people, preferably three or four, complete the training requirements. In this way, if one person cannot or will not train, the agency will still have the capacity to conduct Leader training.

Plan your workshops for the Master Trainers to facilitate before sending them to training. By doing this, you will have their commitment to facilitate workshops and your agency will

have a participant recruitment plan in place. Ideally, these workshops should take place within six months of training and must take place within one year of training.

When choosing someone to become a Master Trainer, there are several considerations:

- **The person must be non-judgmental.**
- It is best if the person has a chronic condition, is a cancer survivor, or a caregiver, depending on the program. If this is not possible, they should have been a caregiver for someone with a chronic condition or cancer. The object in selection is not prior knowledge as much as it is having real experience or empathy.
- The person should have experience and comfort with talking before groups.
- The person may or may not be a health professional or a retired health professional.
- It is best if the Master Trainer is of the same ethnic and/or racial group as the Leaders he or she is going to train. If you population is mixed racially or ethnically then the Master Trainers should represent different groups.
- If you want men to attend your program, it is important that one-third to one-half of your Master Trainers are men. It will be very hard to attract male Leaders if the program does not have visible male role models.
- Leaders who have successfully facilitated several workshops can make excellent Master Trainers.
- **Master Trainers must have a schedule that allows them to take four days, two or three times a year, to train Leaders.**

If Master Trainers do not conduct training as part of their work duties, then you need to pay them at the current rate for professional trainers in your area. The same rate should be paid to all Master Trainers, whether volunteer/peer or professional. While it is true that some Master Trainers may do training as volunteers, this should not be an expectation.

Please note that training Master Trainers is a major program expense. To date only about half of the people trained as Master Trainers ever go on to certification. This is an expensive loss. Before training someone to be a Master Trainer, all of the following should be in place:

- Written commitment from the Master Trainer to facilitate two workshops and one Leader training within the next year.
- Specific dates and recruitment plans for the two workshops. (It is best if these are done within six months of training.)

- Commitment from the Master Trainer's employer to give them the time for leading and training.

T- Trainers

T-Trainers are responsible for training Master Trainers. Most organizations do not need T-Trainers. Only organizations with multi-site program licenses would benefit from having local T-Trainers. If you are planning on training fewer than 12 Master Trainers and less than once every two years, you are probably better off teaming with a nearby organization and training your prospective Master Trainers together. Master trainings need to be coordinated with the Self-Management Resource Center (SMRC). The first step is to submit a Training Request Form. SMRC will recruit, select and confirm two (2) T-Trainers to hold the Master training. For more information, please contact SMRC@selfmanagementresource.com.

III. Leaders

Implementation of all SMRC programs requires **two (2) active,** trained Leaders for each six-week workshop. The Leaders are usually (although not exclusively) non-professionals (peers) with one or more chronic conditions. In some cases, they both are volunteers receiving no pay but it is suggested that Leaders receive a small stipend (150 to 200 US dollars for facilitating a six-week program). For information on requirements to remain an active leader please see the *Fidelity Manual*.

The job of Leaders is to facilitate a six-week workshop using a detailed, scripted manual. **It is not expected that Leaders will find community sites, order materials, or recruit participants.** They may do all of these things, but if so, they need additional training and compensation. One of the real potential dangers of overextending the generosity of volunteers is that we will end up exploiting peer Leaders. If this occurs, the Leaders stop leading workshops or the quality of their facilitation goes down. They may also talk to others in the community and give the program a bad name.

Selecting Leaders

Before recruiting Leaders, consider the following desirable characteristics. Leaders must be literate in the language in which they are going to facilitate (this means that they must speak, read, and write well at about a 10th grade level). They have to be able to read and follow the *Leaders' Manual* fluently. Accents are fine as long as the message flows uninterrupted.

- Leaders should reflect the make-up of the community you are serving. Middle class areas should have middle class Leaders, Hispanic groups should have Hispanic Leaders, rural farm groups should have rural farm Leaders, etc. If you have mixed groups, then the Leader pairing should represent this mixture. The choice of Leaders for any given population highly influences the cultural appropriateness of the program. It also determines the acceptability of the workshop to the participants.

    - When we did a focus group with a group of Native Americans who took one of our workshops, we asked if the workshop was culturally appropriate. They answered that the workshop itself was neither culturally appropriate nor inappropriate. They added that what made the workshop appropriate and culturally relevant was having Native American leaders with Native American participants.

    - If you want to serve men, then at least one third of the Leaders should be men. Women are generally happy to attend groups with any gender mix of Leaders.

Men will usually feel more comfortable in a group with one or two male Leaders.

- Leaders should be motivated primarily by wanting to serve others in their community. Their primary motivation should not be to earn money. Although being a Leader may help them financially, it is never considered a regular job.

- Be a little cautious about potential Leaders who show the following characteristics or behavior:

    1. Their main focus in life is their chronic condition.
    2. They behave as super achievers despite their chronic condition. They are individuals who have had an amputation and run marathons. They are to be greatly admired, but their accomplishment is not something that the ordinary person with an amputation can strive for.
    3. They often pass judgement on others
    4. Persons who have "found the answer" to their disease and want to share it with the world.
    5. Persons who are really sick. Sometimes a chronic condition can become all-consuming and people are too sick to facilitate effectively. This is a hard one on which to make a judgment call. We have had Leaders facilitate while in chemotherapy, while using supplemental oxygen and certainly in wheelchairs. The best rule of thumb is that, if someone really wants to become a Leader, invite them to training and see how they do.

- The people you want to be leaders are those successfully living with a chronic condition. They have their good days and their bad days but in general get on with life and lead interesting and productive lives.

- **It is best if Leaders are assigned a workshop to facilitate before they start training**. If they are not willing to commit to this then they probably should not be trained.

- Final selection of Leaders depends on the recommendation of the Master Trainers at the end of the Leader training.

Leader Recruitment

Now that we have discussed what to look for in a potential Leader, we will discuss how to recruit. Recruitment should be an ongoing effort using not one but many simultaneous strategies. First, decide whom you want to recruit. Remember, Leaders should be representative of the people in their groups. If you want men to attend, at least one third of your Leaders should be men. If you are serving an ethnic community, Leaders should represent that ethnicity.

Remember that when you are recruiting, what you want is name and contact information. You might also ask in what areas they are willing to facilitate so that you will choose enough Leaders to cover all the areas in which you want workshops. Thus, when you tell someone about the opportunity to become a Leader or when you talk with a group, **do not ask people to call if they are interested.** Very few of them will ever call. Rather, if they show even a little bit of interest, ask if you can take their name, contact information, and get back to them with more information.

In a group **do not ask people to sign something at the door if they are interested.** Very few of them will do this. Rather as you are speaking, pass a clipboard with a signup sheet among the group and then collect it after the meeting. If the gathering is large, pass around several clipboards.

If your program has a website, you might put up a page that talks about the need for Leaders and lets people leave their contact information online.

In all of the above cases, give all those who are potentially interested a call within a few days. You can use this call both to inform people about the program but also to check the person out to be sure this is someone you might want as a Leader. Some organizations even have a written job description for Leaders.

There is one caution. Do not decide someone is not Leader material just because the person is not like you. If they meet the criteria above, then ask them to training. This is where you really find out if someone can be a leader or not.

- Look around you. You probably know people who would make good Leaders. Maybe they go to your church, are friends at work or neighbors. They could be clients, friends of friends, etc.
- Post the opportunity to become a Leader at your local volunteer bureau, senior center, and if available, online at sites such as Craig's List and your organization's Facebook page.
- Talk with people in ongoing support groups.

- Post a notice with your community volunteer center.
- As you give talks in the community on any subject, mention this opportunity and take the names of people who might be interested.
- Post a notice in the newsletters of voluntary health organizations such as the Arthritis Foundation, Heart Association, Diabetes Association, etc.
- Many local newspapers run free classified ads for volunteers.
- Ask health professionals to ask their favorite patients.
- Post notices in neighborhood newsletters and health clubs in the area that you wish to serve.
- If you live in a rural area, see if you can get a public service announcement on the farm report or any other program that you know is listened to by the folks you want to recruit.
- After you have started offering programs, ask you Leaders to watch for people in their workshops who they think might make good Leaders. Once these folks are identified, have the Leader approach them with the idea and if they are call them and ask if they would be interested.

It is also a good idea to have several staff people trained to offer programs. That way, if you have to find a substitute Leader in a hurry you can send a staff person.

How are Leaders trained?

Leaders are trained in groups of between 10 and 18 people, by two certified Master Trainers. Leader trainings take 4 full days. Ideally, training should be offered two days one week and two days the following week. A 4 consecutive days schedule may be adopted, although some peer Leaders with chronic conditions may find it physically demanding. Spreading the 4 days of training over a 4-week period is not recommended. The training should never have fewer or more people than the above numbers. Small trainings do not give a good opportunity for modeling and really learning how the workshop "feels'. During the four days the Leader trainees experience every activity in the workshop's six sessions, set and report success on their own action plans, practice teach two activities with a co-Leader, and practice handling difficult people and situations in groups.

In addition, they learn about your organization, how to handle difficult situations, and how to be advocates for the program.

The practice teaches are the most important part of training. They serve to give the participants practice with the program and to gain confidence in delivering the program. They also serve as a fidelity check for the agency. Master Trainers are looking for specific

things in each practice teach. If a few of these are missing, the person cannot become a Leader. If someone does not know what they are doing or does not follow the guidelines by the second practice teach they should not be certified as a Leader. If most potential Leaders have major problems with the second practice teach, there is probably a problem with the training.

Because the people coming to training usually have one or more chronic conditions, it is best not to make the training days too long. To become a Leader, someone must attend **ALL** of the training. It is surprising how many people will have an important appointment just when they are scheduled to do their practice teach. If this happens, and your Master Trainers are available, offer them the opportunity to do their practice teach in your office. This arrangement is very rare and should only be considered when a set of circumstances justifies it. If someone really has to miss a half-day of training, you can go over this in an individual session if at all feasible. Check with your Master Trainers, as the training agenda is tight. However, if they miss more, they should start training again.

Just because someone **attends** all of training does not make that person a Leader. During training, Master Trainers observe inappropriate behaviors. Actions such as judging, telling people what to do, or giving advice are inappropriate. Lateness, talking too much, excessive joking, and not following the trainers recommendations are red flags. From long experience, we have learned that the way someone acts during four days of training is likely the way the person will act when leading a workshop.

In addition, each potential Leader takes part in two practice teaching exercises. There are often problems during the first practice teach but by the second teach all trainees should be comfortable with what they are supposed to be doing. Master Trainers are looking for major problems at the time of the second practice teach such as adding material, not following the manual or being inappropriate with participants. Based on everything they see during the training, Master Trainers recommend each of the trainees either to become a Leader or not to become a Leader. If someone is not recommended, they should never facilitate workshops.

When is someone really a Leader?

After training, those recommended to become Leaders must facilitate a full 6-week workshop within a year. It is best if this occurs within six months. Only after someone has facilitated his or her first workshop is one officially a Leader. Please consult the *Fidelity Manual* on what one must do to remain a Leader.

Something to Think about BEFORE Training

Once Leaders are trained, the training will not do any good unless they quickly facilitate workshops. If they wait more than 6 months, they will start to forget what they learned during training. If they have not facilitated workshops within 12 months, they need to be retrained. **It is best if you have workshops scheduled and filled before leaders start training**. By asking potential Leaders to commit to a workshop **before** they start training you are sure that they are really committed to facilitate workshops. Of course, you can always have some folks who don't make it through training, and you will have to scramble to find Leaders. This is less of a problem than training many Leaders you will never use. You should plan on having somewhere between 10% and 25% of the Leaders you train never facilitate a workshop. You can use this as a rough rule of thumb when deciding how many Leaders to train.

What is needed for training?

- **Master Trainers** - Two active Certified Master Trainers (active means that they have taught at least one leader training in the past two years (either a leaders' training or a workshop every year). The names of active trainers appear on our website but are password protected. Every master trainer has the password.

- **A room** – a room big enough to accommodate comfortably 10-18 trainees. They can sit in a circle or opened square hopefully with tables in front of them. Be sure that the room is accessible as are the bathrooms and that the chairs are comfortable—people with chronic diseases will be using them all day for four days. If you do not want to sit in a chair for six hours a day, neither will your trainees.

- **Equipment/Supplies**
  - ❑ A daily roster sheet to keep track of who is there each day.
  - ❑ **Reusable** name tags for each trainee and trainer and black felt tip pen.
  - ❑ During practice teaching on the 2nd and 4th days, you will need one additional breakout room. (If you are training 10 people or fewer, this is not necessary).
  - ❑ Easel and chart pads (25x30 inches) (63.5x76.2 centimeters) for each room.
  - ❑ **A complete set of prepared charts plus duplicates of some of the charts that are posted throughout training.** The format for the charts for the different workshops is always found in Appendix I of the *Leader's Manual*. The charts should each be big enough to be read from a distance (see suggested measurements above) and hand written. Never use PowerPoint or overheads.

- ❑ A whiteboard, chalkboard, or additional easel with blank flip charts for brainstorms.
- ❑ Whiteboard markers (dark colors) and eraser.
- ❑ Blank flip chart paper and markers for trainees to make their charts for practice teaching.
- ❑ An audio/CD player for use for playing relaxation CD *"Time for Healing" (the classroom version).*
- ❑ Box of tissues.
- ❑ Water
- ❑ You may want to consider having snacks.

- **Materials for Leader Trainees — 1 of each of the following for each trainee** (see *Master Trainer's Manual* for details)
  - ❑ A training agenda
  - ❑ Workshop Overview and Homework handout
  - ❑ Book: *Living a Healthy Life with Chronic Conditions, Living a Healthy Life with Chronic Pain,* or *Living a Healthy Life with HIV*, depending on program
  - ❑ CD: *Relaxation for Mind and Body*
  - ❑ *Leader's Manual* in a loose-leaf binder
  - ❑ Practice teaching assignment sheets
  - ❑ Practice teaching activity Checklists and Feedback Forms

  On last day of training:

  - ❑ Leader training evaluation forms — there is no set form and you can evaluate as you like.
  - ❑ Leader certificate of completion—there is no set certificate but it is nice to make a certificate to give to each of your new Leaders.

How are Leaders monitored?

1. The first opportunity for monitoring Leaders is during training. If someone is not appropriate during training, the same behavior will likely occur during actual workshops. Here are some of the things that Master Trainers will be looking for during training:
    - Are trainees on time?
    - Do they treat each other with respect and without judgmental statements?
    - Do trainees ask appropriate questions?
    - When a problem behavior is brought to the attention of a trainee, is it corrected or does it continue?
    - During practice teach, do trainees follow the manual?
    - Can professionals leave their professional aside and work as a peer?
    - Have trainees mastered the basic skills of action-planning, feedback, brainstorming and problem-solving?

2. Except for very rare instances of hostile or disrespectful behavior, rarely is there just one behavior that would disqualify a person as a Leader. Rather, we look for a pattern of mild but unacceptable behaviors over four days. During the Leaders training, the Master Trainers will be making notes on the trainees and talking with those where there might be problems.

3. Program fidelity is based on the ability of the Leaders to deliver the program as designed. Thus monitoring of the Leaders is a key issue in program implementation.

4. Leaders always facilitate workshops in pairs. This is true even if the Leaders have a great deal of experience. There are several reasons for this:

    - The SMRC Self-Management programs are complex. They require two people to be sure that nothing is missed.
    - If there is a problem with one Leader, (they are late, not following protocol, etc.) you will often hear about it from the second Leader.
    - The Leaders act as models for the participants and two Leaders provide a greater range of modeling.
    - Leaders support each another. This is especially true if a Leader loses the train of thought, goes slightly off track, or there is a difficult participant.
    - By having two Leaders, it is easier to deal with difficult workshop participants.

5. New Leaders should be paired with experienced leaders. This is not always possible but should be considered best practice. Leaders sometimes like to be paired with specific Leaders. This is OK and they should be given their choice if possible. Program needs do not always allow this, so it should not be an expectation. Furthermore, it is important that Leaders who do not like each other not be paired. If no one wants to work with a specific Leader, this is a good signal that something is wrong.

6. After the first session of each workshop it is best to check in with each Leader by telephone. You can find out if there were any problems with the site, the participants or the co-Leader. If any of these arise, follow-up. Consider making another Leader call the fourth or fifth session. Although it may seem that these calls are unstructured, it is surprising the problems that can be uncovered and resolved.

7. Participants can rate the Leaders. You will find an evaluation form for workshop participants to evaluate their Leaders in Appendix II. The problem with doing this at the last session is that only the people who like the workshop and the Leaders will be there. It is probably more important to mail or email this to those who drop out or do not complete the workshop.

8. If possible, observe your Leaders at least once a year. It is best to do this at the second or third session so there will be time for Leaders to utilize feedback. When observing Leaders, use a fidelity checklist such as the one found in the *Fidelity Manual*.

9. If you cannot observe all your Leaders, observe those where you think you might have problems. For example, if one or two Leaders have a greater number of people dropping out or you get complaints, observe these. You might also train some of your experienced Leaders to be fidelity monitors and have them do some of the monitoring. Save your staff time for real problems.

Are Leaders paid?

Before talking about paying Leaders, it is important to discuss what they will be paid for. Leaders are paid to show up for sessions on time prepared and to facilitate throughout the full workshop**. It is not the job of Leaders to find sites, recruit or do publicity.** They may volunteer to do these things and their help is often valuable, but this should not be an expectation. Whenever we ask Leaders to do extra things such as give a community talk, we always give them a gift card or small stipend.

When using the SMRC Self-Management model, there is a fine line between having happy volunteers and having exploited volunteers. The program is designed to include people with chronic conditions at every program level. What and how you pay Leaders depends on your organization and its structure.

If they are truly volunteers facilitating on their own time without pay of any kind, we suggest that they receive a small stipend (e.g., 150 to 200 dollars) for teaching a six-week workshop, or at a minimum, reimbursement for their travel expenses. The other advantage of this is that they are not paid until they return any necessary paperwork.

Some organizations just pay for expenses and travel.

Some organizations give the leaders gift cards or gifts. These can be instead or in addition to monetary compensation.

Some organizations find that there is a liability having volunteers or that there is a problem with labor unions and thus they pay their Leaders at an hourly rate.

Other organizations do not pay Leaders in any way.

In all cases, what is important is that the Leaders are treated well. This can include recognition at an annual event and or giving them small gifts. One of the most costly elements of the program is Leader training, and thus it is important to limit Leader wastage. We will discuss this in the next section.

How to Retain Leaders

The bottom line is to appreciate and support Leaders by paying attention to them and being nice to them. Over the years, here are some things we have learned.

- People decide to become Leaders for their own unique reasons. The more you know about these reasons the more you are able to help them meet their expectations. If someone wants to help people like themselves, then they might be the right person to give talks to disease specific organizations. If they need social contact then they might want to facilitate more workshops or do some extra work recruiting. If they are a student who needs a project, then maybe you can have them evaluate some small part of your program.
- Leaders are special and need to feel special. Thus, when they call, you should talk with them or call back right away. When they come into the office, stop and talk with them. Send thank you notes, birthday cards and/or holiday cards.
- Have a yearly or twice yearly Leader get together. You can use this for retraining but can also honor special Leaders and give everyone a lunch and maybe a bag to carry their materials.
- If people decide they no longer wish to be Leaders, find out why. Do not just accept the first answer such as “I am busy”. Probe a little to find out if there is something

about the program which has made them decide that this is no longer worth doing. Here is an example of a probe: "I know that all of us are really busy, but I also know that sometimes Leaders decide that they want to quit for other reasons such as it being too much work, not getting along with their co-Leader or not being treated well by the staff. We really need to know these things so we can improve. Is there anything else you would like to tell us?"

One of the biggest problems is training folks who never facilitate a workshop. To avoid this, have Leaders commit to a class with a specific, time, date and place before they ever come to training. If they are not willing to do this, then do not train them. This means that you have to organize all your workshops before training Leaders.

How do leaders retain their status as leaders?

1. After being trained, they must facilitate one workshop (six session series) within a year. Leading their first workshop within six months is better.
2. At a minimum, Leaders must facilitate one series of six sessions every year from date they were trained as Leader. This is important, as that date will define their anniversary date every 12 months. This is the time (the twelve-month period) for them to be active facilitating workshops.
3. Alternatively, Leaders may attend a refresher training. These are available on-line or offered by a Master trainer in person for groups of 8-16. This option should not be used more than once every 2 years or the first year after training.
4. Leaders not meeting the above criteria must be retrained.

IV. Recruiting Participants

Recruiting Systems

Before you start recruiting and even before you train Leaders, be very clear about who you want to target. Do you want Spanish-speakers, seniors, people living in a certain area, men, or people getting their health care from a specific health care location or system? Once you know whom you want to target, then everything else should focus on getting your targeted folks to attend. This includes the time and place of the workshops as well as how and where you publicize them.

What often makes or breaks a program is participant recruitment. This is more difficult than you might expect. Recruitment is a function of five factors: **time, systems, scheduling, names, and follow-up.** We will examine each of these.

Time:

- Successful recruiting (all scheduled workshops should have 10-16 participants) takes advanced planning and it takes staff time. There needs to be a person whose job is to recruit. Depending on how many people you want to reach this can be a day, a week, or a full time job. For example, if you want to recruit 500 or more people a year this is probably a full time task. This is another reason why you need a Program Coordinator.

- From the start of recruiting to the start of a workshop also takes real time. You cannot expect to put out publicity and have the workshops full in a week. We recommend starting publicity two months or more before the start of a workshop. This is an on-going effort.

Data Systems:

- One of the keys to successful recruiting is to streamline the process. Computers can be a great help. Think about keeping two different data bases, **Publicity Sources** and **Potential Participants.**

Recruiting Tools

Publicity Sources Database:

- Every community has many publicity sources. These include major media such as radio and TV as well as major and local newspapers. Then there are service organization newsletters, church bulletins, school newsletters, advertising from realtors that contain community news, neighborhood publications, social clubs, volunteer organizations, etc.

- Do not forget electronic media. Used well, this can be inexpensive and very effective. When you collect information about potential participants, be sure to get an email. You can also post on websites, Facebook, and user groups including neighborhood and church list serves. If your eyes glaze over when considering using the web, do not worry. This is not complicated and you can surely get someone who is web savvy. In large cities, you might be able to use Craigslist, a hospital and/or city website. Voluntary health agencies also have local websites, as do such organizations as AARP. More and more neighborhoods have user groups and by contacting the group owner you can often post to these groups.

- Every time you find a publicity source, it should go in the database. Be sure to note when they publish, who is the person to contact for public service announcements, the fax number and or email for that person, and how far in advance of publication do they need information. In some cases this may be days and in other cases weeks or even a month or two. You will also want to include in your database what the coverage is for that media source. If you can enter this by postal code, neighborhood, or town, you can then sort your publicity sources when we want to target a specific area. Every time you find a new source, enter it. Thus, the collective recruitment wisdom will not rest in the hands of one person who might not be around the next time you want to recruit.

- The big advantage of this database is that when you want to recruit in an area you can enter the postal code or city and get all the collective knowledge about recruiting for that area. Of course, you also have to continually add to and update this database.

Potential Participants Database:

- Most organizations recruit on a workshop-to-workshop basis. It someone is not interested now or does not show up at sessions, they are lost as a potential future participant unless they call again. To avoid this problem, and add efficiency to recruiting, we suggest that you set up a potential participant database. The purpose of this database is to keep track of all the people who may have indicated any interest at

any time. This way they can be invited to each and every program in their area for two or three years. The important thing is to capture the contact information for as many potential participants as possible.

  - Here is a hint for collecting names: Give talks in the community maybe at sites where the workshops will be held, take every opportunity to talk to groups about what you are doing. At the start of the talk, say that you would like the name of anyone who might be interested in attending and so you will pass clipboards around the audience and anyone who wants more information can sign (name, address, phone email,). You will probably get half of the people in the room to sign. If you just leave this at the back of the room and tell them to sign on the way out, you will get fewer people.

  - If you are recruiting also for Leaders, tell the group this and ask anyone who thinks they might want to facilitate the program to put a star by their name. You can follow-up by calling them.

- Once someone has given you his or her name, address, phone and hopefully email contact information, enter this into your database. In the same database you can keep information on whether the person actually registered for a program, showed up for a program and how many sessions he or she attended. You can also keep track of how many times you invite the person to attend a program before they actually attend.

- It has been our practice to keep people in the database for two to three years and inviting them to every available program in their area before taking them out of the database. Of course, we will immediately take out any person who requests it.

Health Professionals:

Almost all new programs start with the assumption that health professionals will refer patients. This is generally not true. Why do many health professionals do not refer? They are very busy and avoid anything that adds time to a visit. In addition, they cannot keep track of all times and places of our workshops. It is easier to do nothing. Educating your health professionals is necessary but not enough. You also need to put in place a very easy system for their offices to refer. Here are some of the things that are necessary for such a system.

- Workshops offered on a regular basis –such as the first Monday in even numbered months.

- A single call, email, and or web registration. They should only have to contact you once. This is tricky because just handing patients a number will not get much. What

you want is for the health care system to give you names and contact information, and then you call and get them about the workshop. The way this works with privacy regulations is the health professional says, "We have a great workshop that we would like you to attend. Can I have someone call you to tell you more?" Patients will usually say yes and then the doc, the MA or whoever in the office can fax or call you with the name and contact information. Unless you have a secure email or message system in your organization, do not use email.

- Someone to follow-up quickly on the referrals and make sure that folks get into the workshops. If someone is referred and then has a bad experience, there will probably be no more referrals.

- Closing the loop means letting the referral source know that there has been follow-up and the results of that follow-up.

- In a few cases, referral is part of electronic medical records (EMRs). In many ways, this is ideal but instructions on how to institute this are specific to your organization.

V. Scheduling

When and where programs are scheduled is very important to the success of your recruitment. For the purposes of recruitment, regularity is important so that if folks miss one program they will have a good idea when the next will occur. We will discuss three aspects of scheduling, **timing of programs, place of programs and leader availability.**

Timing of Workshops

Time of Day/Day of Week:

- In scheduling the time of your workshops, you have to know your community and who you want to come. Older people will probably not come at night and working people will probably not come during the day. In our area, we have found that Saturday mornings from 9:30 to 12:00 works very well for large segments of the community. For some communities, Sunday afternoon may work well, and for workplaces, times like 4:30 to 7 may work. It is important to think outside of the normal Monday through Friday, 9 to 5 box. This may means that some staff will work some evenings and weekends.

- Older people generally do not like to attend workshop that start too early in the day or end so late that they cannot get home before dark.

- Be very aware of your competition. If a very popular activity such as Bingo is going on at the same site at the same time, you probably will not get much attendance.

- **Do not schedule around Leader availability.** This is hard, but the workshops are for ease of participants. If your Leaders can only facilitate at night and the participants will only come during the day, you will never have workshops. One of the criteria for selecting Leaders is that they are available when you need them.

Time of Year:

- It is best to schedule programs so that they will end by the second week in December and not start again until the second week of January. Nothing happens in the health promotion world from about December 10 to January 10 or 15. There are also some other holidays that you need to watch for, depending on where you live and who you are targeting. These include Thanksgiving, no programs on Wednesday, Thursday, Friday or Saturday of Thanksgiving week, and of course try to avoid programs that meet before long holiday weekends. If you have to skip a week to avoid a holiday, it is OK. Just be sure to get in all six sessions.

- Then there are the holidays that are not date specific as they relate to different calendars. Some examples are Easter, the Jewish High Holidays, the first and second nights of Passover and some Muslim holidays. Jewish holidays always start at sundown. When you look at a calendar, make sure you know which dates are affected. This website will help you avoid cultural misunderstandings:

  http://www.interfaithcalendar.org/index.htm

- Weather can also be a problem, and you have to be a judge about how much to consider this in your area. Our experience has been that folks of all ages are used to the weather where they live and that weather is less of a problem than one would imagine. That being said you need to have contingency plans in case you are snowed out. In places where weather is important, schedule the workshops at places that people go even in bad weather such as churches, retirement facilities, or meal sites.

- Since strange things can always happen, from a snowstorm to an earthquake to not having quite enough people to start a program when planned. We have found that when you ask for space, you ask for seven weeks instead of six and thus have the option of starting a week late or skipping a week if the need arises.

Place:

- One important consideration is to hold workshops where people usually go. Familiar sites are more successful than unfamiliar ones.

- See Community Sites on page 31

Leader Availability:

- You cannot have programs without Leaders, so in planning you must have 2 Leaders committed to facilitate for the full six weeks. If there are many Leaders, for example in an urban area, you can schedule all your programs and then send a list to all your Leaders asking them which they want to facilitate. Then you have to do a dance to see that Leaders and programs match and do a bit of begging to see that all are covered.

- In rural areas or other areas where you may have only two or three Leaders, you should first ask your Leaders when they can or would facilitate and then schedule as best you can around them. However, always remember that the time and place has to be acceptable to the potential participants.

- Sometimes, the best time for Leaders is not the best for participants. In this case, you may have to train new Leaders, because if the times are not good for participants they will not come. As you learn more about times for each of your communities, you can talk with potential Leaders about when they would be available and train only those who meet the needs of their communities.

- If you think that one or the other of the Leaders might have a difficult time coming to all six sessions you might consider having a backup Leader. Some organizations routinely assign two Leaders and one backup for each workshop.

VI. Finding Participants

You might wonder why it has taken us so long to talk about finding participants. The reason is that if you do not have personnel and systems in place, and if you have not done a careful scheduling of your workshops, finding participants is much more difficult, if not impossible. This section assumes that everything we have talked about so far has happened.

Be sure that your publicity tells people what to expect. They tend to get upset when they think they are going to a lecture by a professional and end up in an interactive peer led workshop.

Many organizations like to put together a publicity kit. This should contain a simple fact sheet about the program along with as many of the following as you may use.

- Public service announcement print
- Public service announcement radio
- Public service announcement TV
- Flyer
- Letter to potential participants Website
- Website link
- Blog announcement
- User group announcement
- Newsletter announcement
- Twitter feed
- Facebook post (in 2015, more than 33% of people over 60 use social media and this has grown from 10% in 2010).

Designing your materials:

You might look to someone who knows something about marketing and/or the use of social media. You are competing with many other things so it is important that your marketing materials do what they are supposed to do, recruit participants. You might ask for help from marketing students at a local college or university or even business school students. In addition, there may be marketers in your community who would donate a little time.

Again, you want to think in terms of systems. All of the publicity should be the same color with the same logo and typeface so over time, those receiving it will think of your program.

Produce all of these digitally so you only need to change location, dates, and maybe the graphics as you publicize each site.

You have done all the ground work and you are ready to place your publicity. Go to the publicity database and place the appropriate publicity with all the sources in your database that reach your target participants.

Be Innovative

Here are some things that sometimes work in some places.

- Anything you can do face-to-face is great. Talks to community groups, announcements made by Leaders at church, talks at community lunch sites, announcements at sporting events, announcements health clubs.
- Use your sites to recruit. Many churches, senior centers, etc., have their own newsletters and/or websites. Be sure your publicity is included. Get buy in from the staff at your sites. This may mean attending a staff meeting and telling them about your program and answering questions.
- Use of mass media such as newspapers, TV and radio — radio talk shows can be especially helpful in some areas. Do not forget foreign language radio — this is especially powerful in reaching the hard to reach.
- Flyers in grocery or pharmacy bags
- Information in utility bills
- Standing in front of big box stores and talking to people (this is especially good if you need just two or three more people to make the workshop a go)
- Announcements at senior lunch programs
- Emails to employees at their workplace
- Flyers under doors of housing projects or large apartment complexes
- Flyers in the windows of neighborhood stores
- Flyers on community bulletin boards
- Letters with information about the program sent from the physician, health center or clinic. We have found that the uptake on a first letter is about 10% so you will need to send about 150 letters to fill a program. You might also have health systems send announcement via their patient portals (how docs communicate with patients via email).
- A reminder in the electronic medical record to health professionals to refer people to the program, or better, a link where they can download information and hand it to

their patient. Past participants can also be a great recruiting resource. If you are giving a course in an area, you can use your database to mail flyers to past participants in that area and ask that they post them or give them to friends.

- If a clinic has a TV in the waiting room that shows health-related content, see if your program can be added.

Some Rules of Thumb

- One of the things that we have found is that the more personal your publicity and contact, the more effective.
- Use multiple modes of publicity and usually the more the better. So what if you have too many people! You just give more programs and can show your funding source that you have a high demand.
- Be nice to responders. This sounds simple but what does it mean? Have your phone answered by a real person. When someone leaves a message, call him or her back quickly. Be sure that the person on the phone is well trained and can answer questions about the program. Again, the more personal the better.
- Once you have someone's contact information, they should be invited multiple times to the program. This information can also be used when you almost have enough people for a program but not quite enough. Call people who are in your database and live in the area. Sometimes all it takes is a personal phone call to get someone to attend.

VII. Professional Backup

Our programs deal with people who have chronic conditions. Thus, it is not surprising that sometimes questions or situations arise that require help from health professionals. It should be emphasized that these do not occur very often but when they do you need to have health professionals you can call for help.

Someone to Answer Specific Medical Questions.

We teach our Leaders that when someone asked a medical question, they should be referred back to their health professional or told to find the answer and share it with the group the next week. (If leaders do not follow this exactly they should not be facilitating.) This serves several purposes. First, it supports self-management by making the individual responsible for using community resources and finding their own information. Second, it relieves Leaders of being responsible for offering information they do not have. Third, it assures health professionals and administrators that leaders are giving medical advice.

Sometimes a question arises from several people such as why blood glucose sometimes goes up in the morning when someone has been fasting. In such cases, the Leader should call the program coordinator who in turn will get the information from an appropriate professional; they will then pass the answer back to the Leaders to share with the group.

Someone to Call in an Emergency

Emergencies do not happen often but when they do, Leaders must act quickly. Over the years, we have had people who have talked about suicide, or talked about being abused or having children abused by a spouse. These are clearly situations outside of the ability of peer Leaders. What we expect from Leaders is to call the Program Coordinator immediately, who will in turn take over this situation. This is not a time to be coaching peers.

What do we do about an emergency during a workshop?

These also occur, but not often. This is usually a medical emergency and all that we ask our Leaders to do is to call 911 or the relevant emergency number within the site. They may want to dismiss the workshop until the next week. It is also important to let the others in the workshop know how the sick person is doing. This is best done by the Program coordinator to assure that patient privacy regulations are followed.

Developing a Crisis Protocol

Every organization should have a written crisis protocol that states exactly what a Leader and Program Coordinator should be expected to do in case of a crisis. This can be a medical emergency, violence, natural disaster, or a participant talking about suicide. The steps must be detailed, with when to invoke the protocol, the steps needed to be instituted and when, the telephone numbers of the persons to be contacted, etc. This also means that the Program Coordinator must have a nights-and-weekends phone number for Leaders to call in an emergency.

Leader trainees are always worried about something happening while they are in a workshop. A crisis protocol can help reduce those fears.

The protocol should be handed out and discussed at Leader training, and also placed with the materials for each workshop, so that it will always be at the Leader's hand.

VIII. Community Sites

Program sites must meet several minimum criteria. They must be:

- Handicapped accessible. This includes wheelchair ramps, doors, elevators and rooms large enough for a wheelchair to maneuver, nearby handicapped parking, etc. You might also see if assistive listening systems are in place or that you have funding for an American Sign Language interpreter in case you get a participant with hearing impairment.
- Safe
- Be able to accommodate up to 20 people in a circle or U shape.
- Have parking, if this is a consideration (if at night this should be lighted)
- Be near public transportation if this is a consideration
- Have well lighted exteriors if the program is after dark
- Be open to having anyone from the community attend
- Have a room that provides privacy and provides enough space for the Leaders, participants, flip charts, white board, and still have room to move around. Comfortable chairs help and remember you will need extra space if any of the participants or leaders uses a wheelchair or scooter.
- Have insurance

The site should also be in the same community you want to serve, so that in most cases, participants will need to travel only a few miles or sometimes blocks to reach the site.

Finally, the site should be somewhere potential participants will feel comfortable. This is not always obvious. Sometimes, a church, temple or mosque may be the perfect place to host the program and people from the community would feel comfortable there. In other cases, people would find a house of worship other than their own uncomfortable. Often times there is a very good site but the community sees it as serving another population such as youth and not someplace that they would typically go.

To find out these things, you have to talk to people in the community and find the natural meeting places for the people you are targeting. If such places do not exist, then look for neutral meeting places such as community rooms in shopping centers or training rooms in large department or warehouse stores. Be aware that sometimes perception is more important than distance. You may have an excellent site near the community you want to serve but people from that community may feel uncomfortable crossing the road or tracks to this site.

The following is a list of some sites that many groups have found useful.

- Senior centers
- Public libraries
- Churches or other houses of worship
- Retirement communities
- Community centers
- Community rooms in apartment or condominium complexes
- Community rooms in banks
- Public schools after hours (be aware of small desks)
- Meeting rooms in the offices of voluntary organizations
- Union halls
- VFW halls

There are also some sites that may seem perfect but may cause problems. You will have to make the decision for your own community.

- Hospitals. These may seem perfect but people usually do not like to go to places they find unpleasant and for most folks going to a hospital has bad memories. Also the parking is often very bad and the distances to meeting rooms long and confusing.
- Clinics. These are less problematic than hospitals but may have some of the same problems as hospitals. Another problem is being sure that the reserved space will really be empty and available when promised. Unfortunately, in health facilities, health professionals always seem to have first priority for meeting space and it is very easy to dump a community program.
- Mental health facilities or VA facilities, unless you are offering a program for people who use these facilities. The non-users of these facilities usually do not want to be associated with them.
- Perfect in every other way but the workshop is held in shared space. Unfortunately, this will not do as workshop participants do not like to share the details of their lives with those not in the workshop. Even rooms with partitions can be a problem.

IX. Materials for Program Participants

The following information details materials that are needed **for each program participant**. Materials needed for training of Leaders are discussed in the training checklist on pages 13-14.

All program materials except charts are available from Bull Publishing:
http://www.bullpub.com/
P.O. Box 1377
Boulder, CO 80306
Telephone 800-676-2855.

- A copy of the appropriate companion book for the specific workshop as follows:

    - Chronic Disease Self-Management Program (CDSMP): *Living a Healthy Life with Chronic Conditions, 4th edition*
    - Diabetes Self-Management Program (DSMP): *Living a Healthy Life with Chronic Conditions, 4th edition*
    - Chronic Pain Self-Management Program (CPSMP): *Living a Healthy Life with Chronic Pain* (also available in Spanish)
    - Positive Self-Management Program (PSMP): *Living a Healthy Life with HIV, 4th edition*
    - Cancer Thriving and Surviving (CTS): *Living a Healthy Life with Chronic Conditions, 4th edition*
    - Building Better Caregivers (BBC): *Living a Healthy Life with Chronic Conditions, 4th edition,* and the *Building Better Caregivers Workbook* (BBC book published soon).
    - Tomando Control de su Salud (Spanish CDSMP): *Tomando Control de su Salud, 4th edition*
    - Programa de Manejo Personal de la Diabetes (Spanish DSMP): *Tomando Control de su Salud, 4th edition*

    For those that cannot read these are also available on audio CD.

- A copy of the companion CD if applicable. There are relaxation CDs in English and Spanish that can be used for any of these programs. They are recommended but not required. Exercise CDs are available in English and Spanish for programs that call for them.

- Relaxation for Mind and Body (also Relajación para la mente y el cuerpo)
- Moving Easy (also El Programa de Movimientos Fáciles)
- Spanish Exercise CD: Programas Educativos para la Salud: ¡Hagamos Ejercicio!
- Spanish Relaxation CD: Programas Educativos para la Salud: Relajación Muscular Progresiva y Un Jardín de Flores

- There are also books available for other countries and languages. As these change frequently, it is best to contact Bull Publishing for what is currently available.

- Every set of leaders (two per program) will need a set of charts for the Program. These charts should be hand-made and are usually made by the leaders. Directions for making charts are in the appendix of every Leader's Manual.

How do you assure participants have all needed materials?

Materials for the workshops are an important part of the program. Ideally, each participant receives a book and/or a CD to keep for on-going use.

This can be supported through the purchase of training materials by a sponsoring organization. Organizations, in turn, donate them to the program for use by participants.

Some areas charge the participant a small fee that covers the cost of the books or CDs and/or the cost of attending the workshop series.

Other areas establish a lending library that allows materials to be checked out and returned. Some places may also assure public libraries have several copies of the books which are then available to library patrons.

Some programs loan the books to participants for use during the workshops, giving them the option to purchase the book at the end of the series.

Other programs use the books as incentives, charging for them only if the participant does not complete at least four of six workshops.

Materials are much less expensive if bought in large quantities; Bull publishing http://www.bullpub.com/ provides discount information.

X. Program License

Before an organization can offer SMRC self-management programs it must have a license. There are at least four reasons for licensing.

1. The license establishes the legal obligations of the organizations offering the program.
2. The license protects intellectual property.
3. The license lets us keep track of who is offering the program and thus form a network of all licensed organizations.
4. The license allows us to notify organizations when there are program changes.

The cost of a license is determined by how many programs your organization plans to offer each year. As of January 2016, a basic license for 30 programs over three years costs $500. There are many types of licenses depending on your needs. You can find full information about current license fees and a form to apply for a license at our website in the "Licensing" section.

XI. Working with Different Ethnic and Cultural Groups

The SMRC self-management programs are designed to be culturally adaptable. This means that they are usually acceptable in any cultural setting as long as the leaders and participants are from the same culture (and sometimes-socioeconomic status). The workshops also need to be offered in a site and at a time that is culturally and socio-economically acceptable for the population being served. Here are a few principles to think about when working with persons from a culture with which you are unfamiliar.

1. Cultural competence is a developmental process. It is impossible for anyone to be aware of all facets of a culture — even in one's own culture. For this reason, we prefer the concept of cultural humility. This means that we approach cultural issues from a humble position without making judgments. Being humble means that we realize that we do not know enough and want to find out more. Another way of saying this is to approach the culture with a curious mind and an open heart.

2. Don't assume (or believe those who say) that you can't be effective working in a culture other than your own. Sometimes you can be MORE effective because you do not have family or other affiliations (or conflicts) and bring a fresh perspective.

3. There is often as much diversity within a culture as there is between cultures. People living in villages in Paraguay may have little in common with people living in villages in Spain or in New Mexico. The common link may be language or social structure, but the similarities still do not make them the same.

4. Since there is so much diversity within cultures, one needs to be very careful about cultural stereotypes such as "all African-Americans…." or "my people…" One size seldom fits all.

5. Be careful about advice from cultural experts. It has often been our experience that people come to training and immediately tell us how the program needs to be changed for "their" community. Often we are told _____ do not do this and it will be found to be offensive. Usually when we examine this closely we find that some _____ do not do this and might find it offensive but that many other _____ have no problem. Sometimes we find that the "expert" has a problem with _____ but not the community they represent.

   Does this means you should not listen to experts? No! It just means that you need to listen to more than one expert and most importantly to the real experts in the community; not people who try to represent the community but in reality do not.

6. Ask the people that know. These are the people you want to serve. We suggest that before you make any adaptations you find a group of people and offer the program as it is written. Then at the end of the program have a focus group and ask the participants what they would change. Every time we have done this, we have found that the changes were not what we expected and were more minor than we thought. Here are some examples.

    - We have been surprised at how well some of the exercises worked with tribal people who many thought would be reluctant.

    - When we held a focus group with rural First Nations People in Canada they wanted longer sessions so that they would have time to sit around and talk before the program started. They quickly reminded us that their diet was mostly wild animals and berries. They wanted few other changes. When we did the same thing with urban Indians in the United States, they changed the symptom cycle to a Native symbol and added a short prayer.

    - With Native American communities, either prayer or silent reflection is added to the beginning of most sessions and more emphasis is placed on low fat low salt foods. In the Northwest, there might be more focus on a traditionally protein rich diet…fish, seal, deer, elk, and whale.

    - In many cultures there is a focus on traditional foods and connecting the diet recommendations with the traditional foods will add cultural credibility to the presentation

    - In some cases there is also a short section added on dealing with racism when receiving health care.

    - Hispanic Seventh Day Adventists asked that we take out the relaxation exercises.

    - Hispanics (mostly those born in Mexico) did not like working in pairs and preferred small groups of three or four people. There also wanted a section on what the various health professionals did in the United States as they were usually saw only a physician in their native countries.

    - Finally, because many people in our focus groups told us that they did not like exercising outdoors either because of safety, bad weather or embarrassment, we created an audio exercise CD that could be used at home.

7. Employ people from the community you want to serve. This does not mean that you should employ professionals from that community but just people with chronic conditions from that community who know the community and want to serve their community. This places an expert cultural guide in your organization and sends a message to the community that you are serious about working with them. Do not worry about academic degrees. Instead, hire someone who represents the population you want to serve, who lives in the community and has been active in the community. Nothing speaks of good intent more than putting money back into the community you want to serve.

8. Take some personal time to learn about and visit the community you want to serve. This is more than going to lunch at an ethnic restaurant. It means walking the streets, noticing the shops, going to festivals and see where people naturally gather. It is amazing how much you can learn about a community with "new eyes".

9. If you do not understand something, avoid the assumption that it is like something else you do understand. Instead, again ask the people who know the people from the community.

10. If you want to learn about someone else, share information about yourself.

11. Listen and then listen some more. Some people use silence to talk or are thoughtful before answering. Do not feel a need to fill in every silent space.

12. Plan for sustainability. Culturally diverse communities, more than most communities, have been used by agencies and academic institutions to get grant money. Programs are given for a short period of time, and even when very successful, are discontinued when funding ends. It is very important when one works with a community that one has a commitment to that community beyond the end of a specific funding cycle or project. The best work is that which enables the community to continue the program.

XII. Evaluation

First, let's talk about what not to do.

All of the SMRC programs have been evaluated and have published results. In some cases, they have been evaluated numerous times. Evaluation is expensive and a waste of money unless properly done. Having said this, many funding agencies ask for evaluations. Push back a little. Show them what has been done already and ask why they have any reason to think the outcomes will be different for you than anywhere else. You can find a bibliography of publications in Appendix I or in the "Resources" section of our website. Next, suggest a simple evaluation that will tell you something to improve your program—what do you have to do to keep leaders? What are the reasons people drop out? What do people find most useful? What publicity gets you're the most people? Etc.

You will find an evaluation primer and evaluation tools at our website in the "Resources" section. The following is a framework you might use when thinking about evaluation.

The RE-AIM Model (reach, efficacy, adoption implementation and maintenance) model provides one very useful way of considering how to evaluate self-management programs. There is also an excellent website.
http://www.re-aim.org/2003/researchers/defined_res.html

We will discuss possible evaluations you may want to consider for each element of the model. These are just examples, there are many other options.

Reach

You may want to find out who your program is reaching and how representative this is of your area or of whom you are trying to reach. You may also want to know what proportion of a total population you are reaching.

1. The most basic reach question is how many people are attending your programs. Then you might want to know their characteristics such as gender, age, education, ethnicity, etc.

2. You might want to do a little more and compare your data with the data of the area. For example, if 15% of your target population is African-American, are 15% of the workshop participants African American?

3. As your program grows, you might have a goal of reaching 10% of the seniors in a specific postal code or who attends a specific Senior Center. Then at the end of the year, you can check to see how you have done.

4. You may want to know which types of publicity bring in which types of people.

Effectiveness

When people think about evaluation, they usually think about evaluating the positive and negative impacts of the program on such things as behaviors, symptoms, health status and or health care utilization.

Some people think that they should test knowledge about the subject matter. Resist this suggestion. We are interested in what people do, not what people know. The evidence that knowledge alone affects outcomes just isn't there.

Effectiveness evaluations are usually done by getting information from participants (usually by questionnaire) before the program starts and again some time later. For SMRC self - management programs, most effectiveness evaluations have been conducted four to six months after the beginning of the program. For more information about effectiveness studies and sample questionnaires, you can go to the "Resources" section of our website.

Adoption

Adoption evaluations look at the settings and or organizations that are offering a program and how successful each is. Unfortunately, we do not do enough adoption studies. Here are some examples that you might consider.

1. You set off to target health plans in your area and talk to many people in many plans. You then examine how many plans offer the program and what are the characteristics of the plans that offer the program and those that don't.

2. You offer Leader training to 20 community organizations and 10 actually send people to training. How do those that send people differ from those that do not?

3. After a year, you find that 6 organizations have offered a program but four have not. It would be good to know what makes the difference.

4. At the end of two years, there are only 4 organizations offering programs. Two of these offer several programs a year while two only offer one program a year. Can you

learn anything by talking to these programs and finding out what makes the difference?

5. You initially train 20 Master Trainers. Fourteen of these get certified and 10 actually train leaders. Since training Master Trainers is very expensive you might want to know why you had only a 50% success rate and how you can do a better job of selecting and supporting Master Trainers.

6. You notice that very few men attend the program. You put in place workshops and publicity to specifically attract men. You evaluate how successful your efforts have been and what worked and what did not work.

Implementation

At the agency level, fidelity refers to the how closely staff members follow the program that the developers provide. This includes consistency of delivery as intended and the time and cost of the program.

At the individual level, implementation refers to clients' use of the intervention strategies.

Checks on Program Fidelity

- Leaders should be observed or called during each workshop
- Monitor and follow up on drop outs
- Monitor effectiveness of recruiting strategies
- Offer refresher to leaders yearly

You can find more about more about maintaining leader fidelity on pages 11-16.
Also be sure to read the *Fidelity Manual.*

Maintenance

Maintenance is the extent to which a program or policy becomes institutionalized or part of the routine organizational practices and policies. Within the RE-AIM framework, maintenance also applies at the individual level. At the individual level, maintenance has been defined as the long-term effects of a program on outcomes after 6 or more months after the most recent intervention contact.

Beyond RE-AIM---You may want to examine how participants, leaders and or providers value the program and what it has meant to them. This will probably require a qualitative evaluation with open ended questions.

XIII. Cost and Sustainability

We cannot tell you how much it will cost to implement the program. Too many factors depend mostly on how many programs you will give and how efficient you are. In the United States, a national figure of $300-350 per person is about average. As you look at costs be sure they are real costs.

Sometimes what happens is there is a new grant or other funding source. The salary of someone on staff has dried up but you want to keep them. You pay their salary from the new funding source. You may only need them half time on the project but pay them full time to keep them. In figuring costs, you should only figure what you actually need and what they are actually doing. In other words, costs should be real. Here is a list of items to consider when thinking about costs.

- Program Coordinator (may be part-time or full-time)
- Master Trainers
- Training of Master Trainers if you do not have any available
- Leader's training (food, room, materials, recruiting leaders, leaders' manuals)
- Publicity
- Participant registration and support
- Leaders (may be volunteers or may receive a stipend)
- Sites for programs (usually donated but you may have to pay rent)
- Materials for participants (should be factored in before implementation)
- Charts to be used by the Leaders
- Evaluation
- License

How to Sustain a Program

Some of the SMRC programs have been around for 25 years or more and continue to have widespread uptake. At the same time, we have seen many changes in how the programs are sustained. While many programs are funded by local, state or national grants, we are seeing a consolidation of services. This means that instead of 20 organizations offering programs in an area there are just one or two. The places with the biggest reach and long

term sustainability are usually places where there are coalitions of agencies working together.

If you are just getting started, look at our website to find out what other organizations in your area are offering the program. Talk to them and find out how you can work together. This will save time and money and in the long run make for more sustainable programs. Of course, this might not work but you will not know until you have tried. Not all programs need Master Trainers. Leader trainings can be done for multiple organizations at one time. Publicity for workshops can cover all the workshops in an area not just those for your organization.

If want to "sell" workshops to health plans, insurers, workplaces, this is not usually a mom and pop operation. To sell to professionals you have to be professional. This means presenting yourself as a coalition that can deliver on what you promise. There are many excellent examples of success in the United States. There are folks to help if you just ask.

Many organizations think that all their funding problems would be over if insurers or the government would just reimburse them for services. Such payment mechanisms might help but they will come with many hoops and regulations. As the United States moves away from fee for service medicine and more toward HMOs and pre-paid plans, it might be better to work for a policy that will allow and maybe even mandate health care providers and insurers to provide self-management support services for those they cover. Again, this is a quickly changing field but you are the feet on the ground.

XIV. What if I have more questions?

Go to the Self-Management Resource Center (SMRC) website:

www.selfmanagementresource.com

Email SMRC: SMRC@selfmanagementresource.com

Call SMRC at: 1-650-242-8040

If you haven't already done so, we suggest you download a copy of the *Fidelity Manual* available in the "Resources" section of the SMRC website.

APPENDIX I: History of SMRC Self-Management Programs

1978+ The Arthritis Self-Management Years

In 1978, Kate Lorig came to Stanford to create an arthritis education program. This program was mandated by a grant from The U.S. National Institutes of Health to the newly funded Stanford Multipurpose Arthritis Center, part of Stanford University School of Medicine.

By early 1979, the Arthritis Self-Management Program had been written and the first 14 leaders trained. Over the next year, nearly 300 people attended programs, and by 1980 Kate had completed her doctoral dissertation for University of California Berkeley, *Arthritis Self-Management: A joint Venture***.**

➔ **This study showed that a small-group, peer-led arthritis program could change health status and health behaviors.**

Publication: Lorig, Kate, et al. "Outcomes of self-help education for patients with arthritis." *Arthritis & Rheumatism* 28.6 (1985): 680-685.

Based on this evidence, the U.S. National Arthritis Foundation disseminated the program nationally and continued to do so into the 21st century.

For the next nearly 30 years, the Stanford Arthritis Center, now names the Stanford Patient Education Research Center, conducted a number of studies of community-based arthritis education programs and established some of the evidence that underlies all of our works today.

The following are some of the key findings from this period and their references.

➔ The **Arthritis Self-Management Program reduced costs.**

Publication: Lorig Kate R, Mazonson Peter D, and Holman Halsted R. "Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs." *Arthritis & Rheumatism* 36.4 (1993): 439-446.

➔ **Self-Efficacy is one of the factors explaining beneficial outcomes.**

Publications:

Lorig Kate, et al. "The beneficial outcomes of the arthritis self-management workshop are not adequately explained by behavior change." *Arthritis & Rheumatism* 32.1 (1989): 91-95.

O'Leary Ann, et al. "A cognitive-behavioral treatment for rheumatoid arthritis." *Health Psychology* 7.6 (1988): 527.

Lorig Kate, et al. "Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis." *Arthritis & Rheumatism* 32.1 (1989): 37-44.

➔ **Reinforcement may not add anything**

Publication: Lorig Kate, and Holman Halsted R. "Long-term outcomes of an arthritis self-management study: Effects of reinforcement efforts." *Social science & medicine* 29.2 (1989): 221-224

➔ **Shorter versions of the Arthritis Self-Management Program are not as effective**

Publication: Lorig Kate, et al. "Arthritis self-management program variations: Three studies." *Arthritis & Rheumatism* 11.6 (1998): 448-454.

➔ **Lack of strong evidence that professionals are better than peers as program leaders.**

Publications:

Cohen Judith L, et al. "Evaluation of arthritis self-management workshops led by laypersons and by professionals." *Arthritis & Rheumatism* 29.3 (1986): 388-393.

Lorig Kate, et al. "Arthritis self-management program variations: Three studies." *Arthritis & Rheumatism* 11.6 (1998): 448-454.

➔ **Spanish Speakers benefit from the Spanish Arthritis Self-Management Program**

Publications:

Lorig Kate, González Virginia M, and Ritter Philip. "Community-based Spanish language arthritis education program: a randomized trial." *Medical care* 37.9 (1999): 957-963.

González, Virginia M, et al. "Translation and validation of arthritis outcome measures into Spanish." *Arthritis & Rheumatism* 38.10 (1995): 1429-1446.

➔ **People with arthritis have similar benefits if they participate in disease specific (Arthritis Self-Management Program, or generic (Chronic Disease Self-Management) workshops.**

Publication: Lorig Kate, Ritter Philip L, and Plant Kathryn. "A disease-specific self-help program compared with a generalized chronic disease self-help program for arthritis patients." *Arthritis Care & Research* 53.6 (2005): 950-957.

➔ **A mailed version of the Arthritis Self-management program was successful in English, Spanish and for African Americans who had called and asked for the mail delivered tool kit.**

Publication: Goeppinger Jean, et al. "Mail-delivered arthritis self-management tool kit: A randomized trial and longitudinal follow-up." *Arthritis Care & Research* 61.7 (2009): 867-875.

➔ **The Arthritis Self-Management Program leads to sustained (2-year) benefit.**

Publication: Osborne Richard H, et al. "Does self-management lead to sustainable health benefits in people with arthritis? A 2-year transition study of 452 Australians." *The Journal of Rheumatology* 34.5 (2007): 1112-1117.

➔ **Arthritis Self-Management can be effective for those 80 and older.**

Publication: Lorig Kate, Laurin Janette, and Holman Halsted R. "Arthritis self-management: a study of the effectiveness of patient education for the elderly." *The Gerontologist* 24.5 (1984): 455-457

➔ **The Arthritis Self-Management Program can be effective when delivered via the Internet.**

Publication: Lorig Kate R, et al. "The internet-based arthritis self-management program: A one-year randomized trial for patients with arthritis or fibromyalgia." *Arthritis Care & Research* 59.7 (2008): 1009-1017.

1990+ The Chronic Disease Self-Management Years

In the early 1990s we developed and studied the Chronic Disease Self-Management Program. Early studies were funded by California state tobacco money and the Agency for Health Care Policy and Research. This study was conducted in conjunction with Kaiser Permanente. We found that treatment participants when compared to randomized controls increased healthful behaviors, improved health status and had less health care utilization.

➔ Publication: Lorig K, Sobel DS, Stewart AL, Brown BW, Bandura A, Ritter P, González VM, Laurent DD, Holman HR**. "**Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial"**.** *Medical Care* 1999; 37(1):5-14

➔ Publication: Lorig K, Ritter P, Stewart A, Sobel D, Brown BW, Bandura A, González VM, Laurent DD, Holman H: "2-year evidence that chronic disease self-management education has sustained health and utilization benefits**"**. *Medical Care* 2001; 39(11):1217-1223.

The original CDSMP study was followed up by a longitudinal study that included several Kaiser Permanente regions. This study had findings similar to the original study.

➔ Publication: Lorig KR, Sobel D, Ritter PL, Hobbs M, Laurent D. "*Effect of a self-management program on patients with chronic disease*. *Effective Clinical Practice* 2001; 4:256-262.

➔ Publication: Sobel DS, Lorig KR, Hobbs M. **"***Chronic condition self-management program: from development to dissemination"*. Permanente Journal 2002; 6(2):11-8.

As part of the U.S. Recovery Act, a second large translation study included 22 sites in the United States. Again, the findings were similar to the original study.

➔ Publication: Ahn S, Basu R, Smith ML, Jiang L, Lorig K, Whitelaw N, Ory MG. **"**The impact of chronic disease self-management programs: healthcare savings through a community-based intervention". *BMC Public Health:* 13(1):114, 2013 Dec.

➔ Publication: Ory MG, Ahn S, Jiang L, Smith ML, Ritter PL, Whitelaw N, Lorig KL. **"**Successes of a national study of the chronic disease self-management program: Meeting the triple aim of health care reform". *Medical Care*: 51(11):992-8, 2013 Nov

➔ Publication: Ory MG, Ahn SN, Jiang L, Lorig K, Ritter P, Laurent DL, Whitelaw N, Smith ML: *National Study of Chronic Disease Self-Management: Six Month Outcome Findings*. *Journal of Aging Health*: 2013,25:1258

There were several other key studies showing the effectiveness of the CDSMP outcomes and cost savings in England.

➔ Publication: Kennedy A, Reeves D, Bower P, Lee V, Middleton E, Richardson G, Gardner C, Gately C, Rogers A. "The effectiveness and cost effectiveness of a national lay-led self-care support programme for patients with long-term conditions: A pragmatic, randomised controlled trial". *Journal of Epidemiology and Community Health* 2007;61(3),254-61

➔ Publication: Richardson G, Kennedy A, Reeves D, Bower P, Lee V, Middleton E, Gardner C, Gately C and Rogers A. "Cost Effectiveness of the Expert Patients Programme (EPP) for Patients with Chronic Conditions". *Journal of Epidemiology and Community Health* 2008; 62:361-367.

Effectiveness as an on-line program (Better Choices Better Health)

➔ Publication: Lorig KR, Ritter PL, Dost A, Plant K, Laurent DD, McNeil I. "The expert patient programme online, a 1-year study of an Internet-based self-management programme for people with long-term conditions". *Chronic Illness* 2008; 4(4):247-256.

➔ Publication: Lorig K, Ritter PL, Laurent DD, Plant K. "Internet-based chronic disease self-management: A randomized trial". *Medical Care* 2006; 44(11):964-971.

➔ Publication: Lorig k, Ritter PL, Plant K, Laurent DD, Kelly P, Rowe S. "The South Australia Health chronic disease self-management internet trial". *Health Education and Behavior* 2013 Feb; 40(1):67-77.

Effectiveness for people with severe mental health problems

➔ Publication: Lorig K, Ritter PL, Pifer C, Werner P. **"**Effectiveness of the chronic disease self-management program for persons with a serious mental illness: A translation study". *Community Mental Health Journal* 06/2013 (ePub).

Effectiveness of the CDSMP for people with Diabetes

➔ Publication: Lorig K, Ritter P, Jacquez A. "Outcomes of border health Spanish/English chronic disease self-management programs". *Diabetes Educator* 2005; 31(3):401-409.

➔ Publication: Lorig, Kate, et al. "Effectiveness of a Generic Chronic Disease Self-Management Program for People With Type 2 Diabetes A Translation Study." *Diabetes Educator* 39.5 (2013): 655-663.

Effectiveness of the CDSMP as a program delivered through the mail

➔ Publication: Lorig K, Ritter PL, Moreland C, Laurent DD. "Can a box of mailed materials achieve the triple aims of health care? The Mailed Chronic Disease Self-Management Tool Kit study". *Health Promotion Practice*: ePub 2015 Feb 17.

Effectiveness of the CDSMP for people with Depression

➔ Publication: Ritter PL, Ory MG, Laurent DD, Lorig K. "Effects of chronic disease self-management programs for participants with higher depression scores: secondary analyses of an on-line and a small-group program". *Translational Behavioral Medicine*: 4(4):398-406

1994+ The Positive Self-Management (HIV) Years

In response to the HIV/AIDs crisis, the CDSMP was adapted for use in people who were HIV positive. This was done in conjunction with Allen Gifford MD, who at the time was a Robert Wood Johnson Clinical Scholar at Stanford. There have been several trials of both the original program as well as a program revised in the mid-2000s. Since that time, mainly because of new drugs, the face of HIV has changed to look more like other chronic conditions. Thus, the workshop was revised again and released in early 2016.

➔ Publication: Gifford AL, Laurent DD, González VM, Chesney MA, Lorig KR. "Pilot randomized trial of education to improve self-management skills of men with symptomatic HIV/AIDS". *Journal of Acquired Immune Deficiency Syndrome and Human Retrovirology* 1998: 18(2):136-144

➔ Publication: Gifford AL, Groessl EJ. "Chronic Disease Self-Management and Adherence to HIV Medications". *Journal of Acquired Immune Deficiency Syndromes* 2002: 31:S163–S166.

➔ Publication: Webel AR. "Testing a peer-based symptom management intervention for women living with HIV/AIDS". *AIDS Care* 2010 Sep: (9):1029-40.

1995+ The Chronic Pain Self-Management Years

In the mid-1990s, Dr. Sandra LeFort in St. John's Newfoundland adapted the ASMP for use by people with chronic pain. The workshop has been used for many years in Canada and more recently in Denmark. In 2015, the workshop was completely revised and a book was written to accompany the workshop. It was released for public use in mid-2015. It is hoped that a Spanish translation of this workshop will be available in 2016.

➔ Publication: LeFort S, Gray-Donald K, Rowat KM, Jeans ME. "Randomized controlled trial of a community-based psychoeducation program for the self-management of chronic pain". *Pain* 1998;74,297-306

➔ Publication: Mehlsen M, Heegaard L,Frostholm L. "A prospective evaluation of the Chronic Pain Self-Management Programme in a Danish population of chronic pain patients". *Patient Education and Counseling* 2015: (5)677-680.

2004+ The Diabetes Self-Management Years

Of the most common chronic conditions, diabetes, is the most behaviorally complex. For this reason we decided to explore the possibilities of using a community-based self-management program to assist with the growing problem of type II diabetes. Funding for these studies came from the National Institute of Nursing Research, the Archstone Foundation and the National Institute for Diabetes and Kidney Disease. We were assisted by many members of both the American Diabetes Association and the American Association of Diabetes Educators. There are 3 diabetes programs, Spanish (the first program developed), English, an adapted translation of the Spanish program, and Better Choices Better Health, the online diabetes program. All of these programs have been shown to lower A1C, and improve health behaviors and health status.

➔ Publication: Lorig K, Ritter PL, Villa F, Piette JD. "Spanish diabetes self-management with and without automated telephone reinforcement". *Diabetes Care* 2008:31(3):408-14

➔ Publication: Lorig K, Ritter PL, Villa FJ, Armas J. "Community-based peer-led diabetes self-management: A randomized trial". *The Diabetes Educator* 2009 July-August;35(4):641-51.

➔ Publication: Lorig K, Ritter PL, Laurent DD, Plant K, Green M, Jernigan VBB, Case S. "Online diabetes self-management program: A randomized study**".** *Diabetes Care* 2010;33(6):1275-1281

2010+ The Building Better Caregivers Years

In approximately 2010, the U.S. Veterans Administration approached us about developing and evaluating an online program for the caregivers of veterans who suffered from traumatic brain injury, post-traumatic stress disorder, or other cognitive problems. The result was the online Building Better Caregivers, which underwent a small study and is currently used by the V.A. caregiving program, as well as other organizations in the United States.

In 2013 we received a grant from the Archstone Foundation to adapt the online BBC to small face-to-face group format. This trial will come to an end in 2016, after which we hope to release the small group program for general community use.

➔ Publication: Lorig K, Thompson-Gallagher D, Traylor L, Ritter PL, Laurent DL, Plant K, Thompson LW, Hahn TJ. "Building Better Caregivers: A pilot online support workshop for family caregivers of cognitively impaired adults". *Journal of Applied Gerontology* June 2012;31(3):423-437

2012+ The Cancer Thriving and Surviving Years

In the early 1990's the Macmillan Trust (a cancer charity in the United Kingdom), adapted the CDSMP for use with cancer survivors. In addition, Dr. Lorig is a cancer survivor and her personal experience led to an interest in this topic. These two factors came together when Stanford was asked by the University of Hawaii to develop an online program for cancer survivors and to assist with its evaluation. This collaboration resulted in Cancer Thriving and Surviving.

In 2012, a second collaboration was formed between Cancer Centers in Colorado, Virginia and Texas, as well as the Stanford Patient Education Research Center. This collaboration developed and studied a small group, face-to-face version of online Cancer Thriving and Surviving. This was released for public use in 2015.

Publication: Bantum EO, Albright CL, White KK, Berenberg JL, Layi G, Ritter PL, Laurent D, Plant K, Lorig K. "Surviving and thriving with cancer using a web-based health behavior change intervention: Randomized controlled trial". *Journal of Medical Internet Research* 2014 Feb;1 6(2):e54

Publication: Risendal BC, Dwyer A, Seidel RW, Lorig K, Coombs L, Ory MG. "Meeting the challenge of cancer survivorship in public health: results from the evaluation of the chronic disease self-management program for cancer survivors". *Psycho-Oncology*. 2015, Apr 10 (ePub). doi: 10.1002/pon.3783.

APPENDIX II: Participants' Leader Evaluation Form

How to Use These Forms to Evaluate Leaders

Warning — this is going to look complicated. However, it is not so complicated and is a wonderful tool for finding out how leaders are doing. The calculations below make the evaluations much better than just taking the scores at face value.

First Step:

Collect the forms from one workshop for most of year leaders. This means that if you have 8 leaders and most of them facilitate one workshop you should have forms from 4 workshops or 40 or so forms in all (Assuming you collect 10 completed forms each workshop).

Second Step:

Find a mean score of all the questions **for each leader**. (Add all the scores from the 10 evaluations collected for Leader A and divide by 10)

Third Step:

Find the mean and standard deviation **for all the leader scores**. You can easily do mean and standard deviation calculations with Excel or most calculators.

The hard part is done! Let's look at some examples:

- Let us say that the mean score for all leaders is 4.2 and the standard deviation is 0.3
- Leader **Mary's** mean score was 4. This means that Mary is an average Leader because the range for average (66% of all your Leaders) is between 3.9 and 4.5. You know this by subtracting one standard deviation from the mean (4.2 - 0.3 = 3.9) and adding one standard deviation to the mean (4.2 + 0.3 = 4.5).
- Leader **Jim's** mean score is 4.6. This means that Jim is an excellent Leader because the mean score is higher than the range for the average Leader which is 3.9 to 4.5. Only about 16% of your Leaders will get a score higher than 4.5.
- **Jesse's** mean score is 3.7. This means that Jessie is one of your poorer Leaders because the mean score is lower than the range for the average Leader (3.9 to 4.5) (only about 16% of your Leaders will get a score below 3.9. You should look closely at how people ranked Jesse on each of the questions to see where there are problems. You will probably want to talk to Jesse about their facilitation.

You might say that Jesse's score of 3.7 is actually a good score on a scale of 1-5. Unfortunately, this is not true. People tend to rate Leaders, teachers etc., very high unless they are upset with them. This is the reason for doing this math. It lets you see what your Leaders are really doing.

Sample Leader Evaluation Form on the next page

Please evaluate your workshops Leaders and let them know where they can do better.

You do not need to write your name.

Workshop Location: _____ Date: _____

Leader Name:	**Excel-lent** **5**	**4**	**3**	**2**	**Very poor** **1**
Arrived early and prepared the room					
Started on time					
Spoke clearly and not too fast or too slow					
Was cooperative and polite with co-Leader					
Encouraged group participation					
Is a good model for self-management					
Was polite and respectful with participants					
Offered support					
Handled problem people appropriately					
Finished on time					

Anything else you would like to say about this Leader?

Please evaluate the other Leader on the other side

Please evaluate your workshops Leaders and let them know where they can do better.

You do not need to write your name.

Workshop Location: _____ Date: _____

Leader Name:	**Excel-lent** **5**	**4**	**3**	**2**	**Very poor** **1**
Arrived early and prepared the room					
Started on time					
Spoke clearly and not too fast or too slow					
Was cooperative and polite with co-Leader					
Encouraged group participation					
Is a good model for self-management					
Was polite and respectful with participants					
Offered support					
Handled problem people appropriately					
Finished on time					

Anything else you would like to say about this Leader?

THANK YOU VERY MUCH

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ADMINISTRATION/IMPLEMENTATION MANUAL

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