

TOOLKIT QUICK START
ToolKit



THE QUICK-START GUIDE OVERVIEW

The Quick-Start Guide to Optimizing Life has been developed by the Institute for Optimizing Health Outcomes to help organizations implement self-management programs for patients and families and to generate a supportive environment to promote and encourage self-management behaviors. The Quick Start Guide provides the background, philosophy, and principles of patient self-management and self-management support. It includes the tools and tips needed for an organization to set up a lay-led self-management program, to educate healthcare professional staff and administrators about supporting self-management for patients and caregivers, and to engage community resources to participate in self-management partnerships.

WHY IOHO'S QUICK-START GUIDE?

The recognition of the need for a systematic guide to starting and implementing patient self-management programs grew out of the Institute's experience in delivering programs and helping other organizations get started.

STEP 1: GETTING READY FOR SUCCESS

Perhaps the most important factor to successful patient self-management is a supportive

healthcare environment. You can help ensure success with carrying out a few preparatory activities.

Instill Core Values

The Optimizing Life program is built on the core values of patient self-efficacy, holistic model of health, and patient- and family-centred care. The patient is the only one who really knows what it is like to live with his/her health condition. The patient (and family) must be fully informed and involved in all healthcare decisions. In order to deliver Optimizing Life (Stanford Chronic Disease Self-Management Program), the organization must commit to the core values and to operate by key principles underlying the program. Programs must ensure: voluntary participation, peer-led, competency-based, and community-linked.

Assess Current Status

As part of an initiative to engage in patient self-management, organizations may benefit from conducting an assessment of current culture, structure, and practices. To what degree does your organization involve patients in planning and making decisions about their care? Do the mission statement, leadership, and education endorse patient-centered approaches? Do patients have access to their own medical records? Are they informed about options? Are they encouraged to

seek additional information before making a decision? To what degree do patients and families receive support in setting health goals, making action plans, and assistance in overcoming barriers?

“It is not the strongest species that survive, nor the most intelligent, but the ones who are most responsive to change.”

~ Charles Darwin

Embrace Change

To help patients make changes, the healthcare environment must also embrace change. And to successfully implement self-management, healthcare professionals must have the capacity to learn new skills and behaviors.

At the core of all successful change management strategies are four key principles:

- (1) demonstrated commitment to change (at the senior-most level);
- (2) clear, shared vision that benefits everyone to promote buy-in;
- (3) adequate resources of time and finances; to ensure capacity to act; and
- (4) action plan that specifies: “plan, do, check, act” to implement change.

STEP 2: GENERATING LOCAL COMMUNITY SUPPORT

Successful and sustainable self-management programs need more than the drive and enthusiasm of a few people within any organization. The most successful programs are those that are well resourced and supported.

Raising Awareness

The first stage in this process is to raise awareness within your organization, to secure the support of senior management and or trustees. This can be done by making presentations to key personnel, circulating promotional material to raise awareness and to gain ownership as an ongoing process. A co-ordinator who will be responsible for managing the program should be identified. The co-ordinator should take the lead in identifying funds to support the program. He or she also needs to keep everyone within the organization updated on developments in the wider context of self-management.

Raising awareness outside the organization among local health professionals is also necessary. This will increase the long-term future of the program and help to build effective partnerships.

Challenges in Raising Awareness

Raising awareness among health professionals has proved

particularly challenging for the Chronic Disease Self Management Programs as they started. The term 'patient self-management' itself has caused some misunderstanding, with reports of doctors fearing an influx of patients armed with reams of information from the internet. With expansion of CDSMPs across initially British Columbia and then Alberta and the rest of Canada, education with healthcare providers and patient groups took place to promote understanding around the purpose of the program and mutual benefits. Educational materials, presentations, and skills training sessions helped to generate within local communities and also within governments.

Publicity in local media about individuals who have benefited from doing a course is particularly good for raising awareness among both health professionals and the general public. Another effective way of reaching people who might benefit from course participation is to target local GP practices and make presentations, both to the staff and to patients' groups. CDSMP trainers have found linking with local social and ethnic groups productive. Spending time handing out leaflets at locations where the target audience is to be found (e.g. shopping centres, marketplaces) is also worthwhile.

Tips on How to Raise Awareness

- Arrange presentations to board members/senior managers and to local health professionals
- Make use of available resources and summaries of research to increase understanding about lay led programs
- Invite leaders or people who have attended courses to speak within the organization – experience has shown that they are, without doubt, the best advocates
- Obtain copies of the Optimizing Life brochures and posters and distribute them
- Create your own leaflets including local information and tailored to your target audience (using information leaflets and samples from other localities as a template)
- Make use of your organization's newsletter to publicize the concept of lay led self-management and your courses
- Contact your local CDSM trainers and leaders

STEP 3: IDENTIFYING THE PROGRAM COORDINATOR

The role of a self-management coordinator is a crucial one. It is essential to identify someone within the organization who has day-to-day responsibility for the self-management program and to be the main point of contact for your volunteer leaders. Organizations running self-management programs need to have a dedicated member of staff, or volunteer, as a coordinator. This

person has to support the leaders by taking on a range of administrative tasks that are essential to running successful courses (such as marketing the course, recruiting and screening participants, finding a suitable venue etc). The coordinator will also need to be able to take the lead in the practical planning, organization and marketing of courses. Many leaders find the administrative tasks necessary to run courses exhausting and prefer to concentrate their energies upon delivering the course.

When deciding who will be the coordinator, it is important to be realistic about the amount of time and level of management expertise the job will require. It is impractical to expect anyone without relevant experience, or with an existing full-time workload, to adequately handle these responsibilities.

Additional Resources

As well as dedicating resources to the coordinator, organizations need to take into account what additional requirements will be needed (staffing, training, presentation materials, expenses etc) to support the development of a self-management infrastructure. Investment in ongoing leader recruitment, professional development, support and supervision will, in turn, help to

build capacity within the organization and support long-term sustainable programs.

Coordinator's Tasks

- Recruitment of volunteer leaders and participants for the courses
- Developing and distributing marketing materials for the courses
- Providing administrative support to the leaders
- Providing support to the leaders during the course
- Making sure the program is developed within best practice guidelines
- Ensuring monitoring and evaluation forms are completed and analyzed
- Participating in meetings and training days
- Keeping up-to-date records of leaders' details and courses delivered
- Keeping staff and trustees within the organization briefed
- Working to raise the profile of self-management in general, and the profile and funds for your program in particular
- Accessing local networks and the support that can be gained from them delivering the course
- Exploring joint working across agencies (this creates high levels of reciprocity, cost effectiveness and outreach, and is most effective within formalized agreements, which need to be negotiated)

- Increasing access for people from minority communities (work is ongoing within both the CDSMP and voluntary organizations to improve or extend access for minority groups. These include courses in translation for different ethnic groups; adapted courses for people with aphasia and courses for carers)

STEP 4: RECRUITING LAY LEADERS (QUALITIES)

The CDSMP requires two trained leaders for each workshop. Leaders are usually non-professionals (peers) with one or more chronic conditions. They may be totally volunteers receiving no pay but they may also receive a small stipend (\$150 to \$200 per six-week program). The motivation of leaders should come from wanting serve others or even to help themselves but not to earn money. Leaders must be literate. They have to be able to read and follow the Leaders' Manual.

Leaders should reflect the make up of the community you are serving, in terms of gender, culture, ethnicity, education, and socioeconomic characteristics.

Be cautious about people who:

- Have their chronic condition as a main focus in life
- Are super achievers despite their chronic condition. They are to be greatly admired but their accomplishment may not be

something that the ordinary person can strive for.

- People who are judgmental.
- People who are really really sick. Sometimes a chronic condition can become all consuming and people are too sick to teach effectively. But this depends on the individual.

Supporting Organizations

To deliver the Stanford-based CDSMP (including Optimizing Life) an organization must meet the basic licensing and training requirements of Stanford University, which are:

- Copyright of Patient Education and Research Centre lay led self-management courses belongs to Stanford University
- Organizations wishing to deliver courses should obtain their own license from Stanford
- Stanford personnel revise the manual every three to four years and send the latest edition to licensees. License arrangements differ among the Canadian provinces

Recruiting Lay Leaders

Recruiting is an on-going effort requiring the use of many strategies simultaneously.

Post an announcement with your local volunteer bureau, senior center, community centre, or health club.

Put a notice in newsletters or websites of voluntary groups serving those with chronic conditions such

as arthritis, heart and stroke, or diabetes.

Local papers or radio stations may provide free classified ads or public service announcements for volunteers.

Ask doctors or nurses for names of patients. Recruit past participants.

Training Lay Leaders

Leaders are trained in groups of 10 to 25 over four days by certified Master Trainers. They can be four consecutive days or two days per week for two weeks (but not extend beyond two weeks).

During this time trainees experience every exercise in the workshop, practice teaching, twice, and have a session on handling difficult people in groups.

Newly trained leaders ideally should teach a session within a few months, so it is best to have courses arranged and filled prior to training.

STEP 5: DEVELOPING MASTER TRAINERS

A leader training workshop requires two certified Master Trainers who have completed a 4 or 4.5 day Master Training conducted by two certified T-Trainers. In Canada, the Training Coordinating Center is at the University of Victoria in British Columbia headed by Dr. Patrick McGowan. The Institute for Optimizing Health Outcomes has certified T-Trainers and Master Trainers and provides training

workshops on a regular basis. These are offered at IOHO or at other locations, upon request.

1. Master Trainers must lead two complete six-week courses for persons with chronic illness. These workshops should take place within six months of initial training and never more than one year after training. If a potential Master Trainer has done a year after training without teaching a workshop, they are no longer eligible for certification. Therefore, it is best to arrange workshop sessions with dates and sites prior to sending someone for Master Training. Master Trainers are also required to deliver at least one training workshop per year to retain certification.

Qualities of Master Trainers

If an agency wants to have their own Master Trainers, it is best if they train more than two people. If one person cannot or will not train, the agency still have the capacity to conduct leaders' training.

- It is best if the person has a chronic condition or has been a caregiver for someone with a chronic condition.
- The person should have experience and comfort with talking before groups.
- The person must be non judgmental

- 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, racial group as the leaders he or she is going to train.
- If you want men to attend your program, it is important that 30 to 50 percent of your Master Trainers are men.
- Leaders who have successfully taught several programs can make excellent Master Trainers.
- Master Trainers must have a work 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 they should be paid the going rate for professional trainers in your area—the same rate should be paid to all Master Trainers, peers and professionals.

Monitoring Leaders

Master Trainers should be available to support and monitor the performance of leaders. Program fidelity means leaders must deliver the program as designed. For this reason monitoring of the leaders is a key issue in program implementations.

1. Leaders, even experienced ones, always teach in pairs. The program is complex and often requires two people to be sure

nothing is missed. Also, because leaders serve as models, two leaders provide a greater range of modeling behaviors.

2. During training, if someone is not appropriate (is judgmental, comes late, talks too much, or is very critical of others), this same behavior will likely be seen during actual workshops. Similarly, while many people experience difficulties with the first practice training, if the trainee still has major problems in the second sessions (such as adding material, not following the manual or being inappropriate with participants), the person should not become a leader.
3. If possible, new leaders are best paired with experienced leaders.
4. After the first session of each new class it is best to check in with each leader by telephone. If there are problems with the site, the participants or the co-leader, these can be addressed immediately.
5. Another call can be made to the leaders after the fourth or fifth class. Although, it may seem that these calls are unstructured, it is surprising the problems that can be uncovered and solved.
6. If at all possible, leaders should periodically be directly observed. This is best done at the second third or fourth session. When observing leaders use a fidelity checklist such as that found on [http://](http://patienteducation.stanford.edu/trainer)

patienteducation.stanford.edu/trainer website.

How to Retain Leaders?

The bottom line is to be nice to them. Leaders are special and need to feel special. 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.

STEP 6: RECRUITING PARTICIPANTS

What often makes or breaks a program is participant recruitment. This is more difficult than it seems. Recruitment is a function of five factors: time, systems, scheduling, names, and follow-up.

Time. Successful recruiting (all scheduled courses start with 12-15 participants) takes planning and it takes staff time. There needs to be a person whose job is to systematically 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.

Recruiting also takes real time. You can not expect to put out publicity and have the workshops full in a week. It is usually necessary to start publicity a full two months before the start of a work shop and

this is an on-going effort. The third important role of staff is to have a knowledgeable and friendly person to answer the phone, take registrations and answer questions.

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

Publicity Sources Database.

Every community has hundreds of publicity sources. These include major media such as radio and TV as well as major and local newspapers. Then there are newsletters, church bulletins, advertising from realtors that contain community news, etc. Do not forget websites and user groups.

Voluntary health agencies also have local web sites as do seniors groups or the Y. 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 data base. Be sure to note when they publish, the person to contact for public service announcements, the fax number and/or email, and how far in advance they need information.

You will also want to include in your data base 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. The big advantage of this data base 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 data base.

Potential Participants Database.

Most organizations recruit on a workshop to workshop basis. If someone is not interested now or does not show up at class, they are lost as a potential future participant unless they call again. To avoid this problem and add efficiency to recruiting, set up a potential participant data base 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.

Timing of Programs.

Time of day/day of week. In scheduling your time 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 some areas, Sat. mornings from 9:30 to 12 works very well for large segments of the community. For some communities, Sun. afternoon may work well and for workplaces times like 4:30 to 7 may work. Think outside of the normal Mon.-Fri. 9-5 box. Older people generally do not like to attend classes that start too early in the day or last so late that they can not get home before dark. Also be very aware of "competing" activities.

Time of year. It is best to schedule programs so that they will end by the second week in Dec. and not start again until the second week of Jan. In Canada, many seniors go south for the winter. You may need to schedule around holidays that do not fall on the same day each year, such as Easter, the Jewish High Holidays, and Moslem religious days.

Place (Community Sites). Program sites must meet several minimal criteria. They must:

- Be handicap accessible
- Be safe
- Accommodate up to 20 people in circle or U

- Have parking and/or be near public transportation, if important
- Have well-lighted exteriors if after dark
- Be open to anyone from the community

The site should also be in the same community you want to serve so that participants can easily get to the site. The following are some sites that many groups have found useful:

- Senior centers
- Public libraries
- Churches
- Retirement communities
- Community centers
- Community rooms in apartment complexes
- Community rooms in banks
- Public schools after hours
- Meeting rooms in voluntary organizations

Effective Lay-Led Programs: Desired Qualities of a Community Partner

- Excellent understanding of lay led self-management and its value base
- Understands the issues for people living with long-term conditions
- The desire to support people living with long-term conditions is mission rather than funding-led

- Committed to empowering people living with long-term conditions through the program
- Committed to operating according to agreed best practice
- Values volunteers and knows how to manage and support them
- Understands the need for effective administrative systems to deal with volunteer issues (e.g. payment of expenses)
- Has a business plan and cost-effective business model
- Understands how to relate to statutory commissioning and purchasing processes, and/or some understanding of where other funding may be found

Ongoing Support and Supervision

As almost everyone in our programs has experience of a long-term health condition, it is vital that support is provided at every stage of recruitment and development. The training, accreditation and monitoring process gives leaders time to internalize the essentials of being a good self-manager. This is crucial if they are to become role models for participants in the self-management courses. The fact that each stage of accreditation is managed by an individual who has gone through the same process means that leaders have access to a unique personal source of advice and support. The experience of the self-management leaders at all levels is invaluable in shaping and further developing programs within

the voluntary sector and the CDSMP. Supervision sessions are an integral part of the training and support framework. These sessions are not only a means of supporting consistent delivery, but also provide valuable feedback to inform the further development of good practice. This reinforces the central principle of lay led self-management; the belief that individuals can make a difference.

Evaluation and Maintenance: Reach, Effectiveness, Value Reach

Reach

The RE-AIM (reach, efficacy, adoption implementation and maintenance) model provides one very useful way of considering how to evaluate the CDSMP. There is also an excellent website.

<http://www.re-aim.org>.

The following questions will help you whom your program is reaching and how representative this is of your area or your target audience.

1. The most basic reach question is how many people are attending your programs. You may want to collect information such as gender, age, education, ethnicity, and residence.
2. You may want to compare your data with the data of the area. For example if 15% of your target population is immigrants, are 15% of the CDSMP participants also immigrants?

3. As your program grows you may have a goal of reaching 10% of the seniors in a specific postal code or who attend a specific Sr. 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 kind 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.

Effectiveness evaluations are usually done by getting information from participants (usually by questionnaire) before the program starts and again some time later. For CDSMP 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 following websites.

<http://patienteducation.stanford.edu/research/index.html>

<http://patienteducation.stanford.edu/research/primer.html>

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 talks to many people in many plans, 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 ten actually send people to training. How do those that send people differ from those that do not. 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. 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?
3. You initially train 20 Master Trainers. Fourteen of these get certified and ten are actually training 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.

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

Maintenance

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.

Costs

How much it will cost to implement the program varies considerably, depending on your own set up. There are many factors that depend mostly on how many programs you will give and the volunteer support you can rely on. 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
- Charts to be used by the leaders
- Evaluation
- License

