BUILDING THE FUTURE FOR PATIENT SAFETY.

DEVELOPING CONSUMER CHAMPIONS—A WORKSHOP AND RESOURCE GUIDE.
Consumers Advancing Patient Safety / Chicago, IL 2007

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PART 1 – WORKSHOP PROCESS AND IMPLEMENTATION
This section explains the CAPS workshop process and underlying Appreciative Inquiry processes as applied to a series of successful regional programs to develop networks of consumer champions for patient safety.

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FOREWORD: ATTAINING SUSTAINABLE TRANSFORMATION IN HEALTHCARE

The phenomena of patient safety, medical error and patient harm have captured the attention of healthcare leaders, systems, governments and organizations around the world as a priority. It is recognized that unintended harm and systems failures result in profound human tragedy affecting both the patient as well as the provider populations. Improving patient safety is a global challenge regardless of political environment, economic condition or geographic location, and calls for robust, integrated participation of providers, healthcare leaders, government agencies, regulators, professional organizations and …patients.

Historically, the patients have had little opportunity to contribute their wisdom or perspective back to the healthcare system or voice their aspirations in the efforts to improve patient safety. However, there is a recent appreciation and respect for patient participation in the creation of a safer healthcare system acknowledging that patients are key and even necessary in identifying patient safety issues, advocating for change and designing and implementing solutions.

Consumers Advancing Patient Safety and the World Health Organization’s (WHO) Patients for Patient Safety initiative believe that the perspective, the wisdom and the will of patients and families from around the world provide THE most powerful contribution to ensuring a truly authentic and sustainable transformation in patient safety.

Susan E. Sheridan, MIM, MBA
Co-Founder and President
Consumers Advancing Patient Safety; and
Lead, Patients for Patient Safety
WHO World Alliance for Patient Safety
DEDICATION

Roger E. Fritz (1953 – 2006)

This publication is dedicated to Roger Fritz, who offered his professional acumen, his creative spirit and his soul to the development and execution of the first consumer/provider patient safety workshop on which this guide is based. Friend, visionary, and pioneer in teaching how to transform aspirations into tangible realities, Roger will be remembered as we all go forward in partnership in the co-creation of a healthcare system that is safe, compassionate and just.
**PREFACE: ABOUT THIS GUIDE**

This guide describes the Consumers Advancing Patient Safety (CAPS) workshop process and methodology used to develop future-oriented consumers as partners and champions of patient safety.

CAPS uses and adapts a methodology known as Appreciative Inquiry (AI) in this transformative work, hence its emphasis throughout this guide. This guide is intended for two audiences. First, healthcare delivery or policymaking organizations interested in recruiting partner-oriented consumers and learning from their experiences by structuring a distinct type of workshop experience, and second, consumers who want to more effectively partner with healthcare to improve patient safety.

The workshop process and methodology presented herein are adaptable to a variety of settings and are meant to be customized around different healthcare systems and cultures. In 2007 and 2008 a workshop will be held in each of the six regions of the World Health Organization (WHO). Progress made by workshop participants and lessons learned will be tracked and shared by WHO and CAPS through their websites and online communities.

Building on a foundation laid by CAPS and the World Health Organization’s Patients for Patient Safety (PFPS) program, we hope this modular guide helps in continuing to develop a global network of consumer partnership communities locally, regionally, nationally and internationally. CAPS is grateful to the US Agency for Healthcare Research and Quality (AHRQ) for the support that made this guide possible.

**Partner Organizations: Background**

**Consumers Advancing Patient Safety**

*Consumers Advancing Patient Safety* (CAPS) is a 501(c)(3) nonprofit organization activated in 2003 after an AHRQ-supported workshop that brought consumers, healthcare providers, accreditors, educators and legal system stakeholders together in partnership to achieve specific, patient-centered patient safety goals. The vision of CAPS is to create a partnership between consumers and providers to build global healthcare systems that are safe, compassionate and just.

The methodology centered on AI designed for the CAPS consumer-led formational workshops mentioned above and throughout this guide fosters the role of consumer as partner. The methodology was adapted by WHO at the London workshop that brought together 21 consumers from countries around the world representing all six WHO regions. These patients and consumers who choose to partner with healthcare providers and policymakers have an enormous amount of wisdom to contribute to improving patient safety. Consumers approach this role with a profound sense of responsibility and desire to help create a healthcare system that is safe, honorable and compassionate for patients and healthcare workers alike.
**Canadian Patient Safety Institute**
The Canadian Patient Safety Institute (CPSI) was established in 2003 as an independent not-for-profit corporation, operating collaboratively with health professionals and organizations, regulatory bodies and governments to build and advance a safer healthcare system for Canadians. CPSI performs a coordinating and leadership role across health sectors and systems, promotes leading practices and raises awareness with stakeholders, patients and the general public about patient safety.

**World Alliance for Patient Safety**
In October 2004 the World Health Organization (WHO) launched the World Alliance for Patient Safety dedicated to “bringing significant benefits to patients in countries rich and poor, developed and developing, in all corners of the globe.” The Alliance was established by resolution to pay the closest possible attention to patient safety and establish science-based systems for improving safety and the quality of care. The resolution also reflects and advances various calls to action to make patient safety a public health priority for events that have taken place in the past as well as visioning a healthcare system of the 21st Century that is systems-based and patient-centered.

**Patients for Patient Safety (PFPS)**, one of the six original action areas embodied in the World Alliance, is designed to ensure that the perspective of patients and families, consumers and citizens – whichever term resonates best – in both developed and developing countries is included in shaping patient safety activities. Each patient and lay caretaker brings a unique perspective, critique and recommendation to the performance of the healthcare system and how if can be improved. Unless patients are acknowledged and included as full partners in reform dialogue it is difficult to understand how a true picture of health system performance can be understood, improved and measured.

From the beginning, the role of patients and their caregivers was deemed to be a crucial component of the World Alliance. In response to this call for action, a consumer-led steering group was convened in October of 2004 to develop the PFPS action area of the World Alliance. CAPS Co-founder and President, Susan E. Sheridan, was invited to lead PFPS to implement its call to action and guide its growth and development. Under the aegis of the World Alliance for Patient Safety, CAPS personnel led in the development of Patients for Patient Safety’s Statement of Case[4] [Note: hyperlinks to web-based materials will be available in the online version] and proposed an international event modeled on the Consumers Advancing Patient Safety workshop process to recruit and convene consumer champions who can contribute to better, safer healthcare systems world-wide. CAPS’s AI-centered approach to consumer engagement and partnership has been embraced by Patients for Patient Safety for its global work.

With support from the US Agency for Healthcare Research and Quality (AHRQ) and other funders the PFPS steering group planned and implemented its inaugural event – a workshop held in conjunction with a European Union (EU) Patient Safety Summit held in London, United Kingdom, from November 27-30, 2005. The EU Patient Safety Summit convened over 500 policymakers, experts, clinical leaders and patient advocates from all over the world.
A powerful message of the summit was that patient safety could not be achieved without consumer involvement at its core. The summit participants heard directly from patients and family members of patients who had been seriously harmed or killed by healthcare. They found a desire in the participants that despite these tragic experiences that many individuals are working together as partners with providers to ensure similar events don’t affect other people. They saw first hand that individuals can come together to secure the future of safe delivery of healthcare services.

**Developing Future-Oriented Consumer Champions**

The Consumers Advancing Patient Safety workshop methodology described in this guide was used to structure events international, national and local in scope. It is CAPS’ intent that the materials in this publication will facilitate the continued and successful spread of the concept to spawn other community activities – large and small - that will assist and support efforts to harness the wisdom of consumers who have experienced medical error and develop a collective voice for consumers, citizens, lay caregivers, providers and others interested in participating in the journey to improve patient safety.

CAPS also suggests that readers visit the CAPS resource center for CAPS members at [http://www.patientsafety.org/](http://www.patientsafety.org/) for a wealth of materials related to issues important to consumers working to improve patient safety through partnership. There, readers will find access to citations for articles written by CAPS members, staff and other experts, patients sharing their stories of success in launching initiatives after harm drew them to the patient safety community and advocacy. In addition, audiovisual materials, communities of practice and presentation slides and web sites are presented to support further personal, organizational and philanthropic development in support of patient safety improvements.

**Acknowledgements**

This guide reflects the insight of many individuals and organizations who shared their time and knowledge to create this guide to the CAPS workshop process.

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CAPS Consumer Workshop Experience at a Glance

The CAPS workshop methodology was developed through experience and expertise unique to CAPS in developing consumer partnership communities. This guide will draw from these experiences and will refer to these sessions throughout the text. Here is a capsule of the workshop activities along with a listing of the labels referring to their locations that will be used to refer to each session:

**Houston Workshop / October 16-18, 2003**

**Consumer-Led Workshop to Advance Patient Safety - CAPS Formational Workshop**

In October of 2003, a Consumer-led Workshop to Advance Patient Safety was held in Houston at The University of Texas M.D. Anderson Cancer Center, supported in part by a grant from the US Agency for Healthcare Research and Quality (AHRQ). The results of the workshop included a vision that participants accepted as compelling; a mission that clearly defines what an organization needs to do in order to serve the vision; six goals and sets of action steps that can lead to the goals being reached. The most important result was that participants committed themselves to a sustained effort, and CAPS has committed to organizing and carrying this work forward.

**London Workshop / November 27-30, 2005**

**Global Patients for Patient Safety Workshop**

In 2005, CAPS continued to develop an international community of consumer champions together with the World Health Organization (WHO) World Alliance for Patient Safety, AHRQ and the International Alliance of Patients’ Organizations (IAPO). Under the leadership of CAPS Co-founder and President, Sue Sheridan, WHO recruited 21 consumers from 19 nations to serve the international patient safety movement as consumer champions. Most of these consumers have firsthand experience with medical error coupled with an ardent desire to partner to improve safety. After meeting together with European Union health ministers and other experts, in a workshop designed and facilitated by CAPS, these champions are now supported to go forward and develop regional strategies in their own communities.

**San Francisco Workshop / May 8-12, 2006**

**WHO/PAHO North and South American Regional Patients for Patient Safety Workshop**

This workshop included a community of approximately 65 people working together, including: consumer champions who attended the first WHO Patients for Patient Safety workshop in London, approximately 40 consumers recruited by the Pan American Health Organization (PAHO) from North and South America, WHO and PAHO representatives, meeting facilitators, translators and invited guest experts. The aims of the workshop were to orient workshop participants to the vision/mission of the WHO World Alliance for Patient Safety Patients for Patient Safety (PFPS) initiative, and to expand the network of consumer champions in the Americas who are actively engaged in contributing their experience, wisdom and knowledge to improving patient safety. Workshop participants began to develop and prioritize strategies for establishing effective partnerships between consumers, providers, governments, non-governmental organizations and other groups to improve patient safety throughout the Americas.
**Vancouver Workshop / October 17-19, 2006**

**Patients for Patient Safety in Canada Workshop:**

**Partnering to Advance Healthcare System Safety**

Building on the success of the London and San Francisco workshops, CAPS and its organizing partners – the Calgary Health Region, the Canadian Patient Safety Institute and the Winnipeg Regional Health Authority – brought together committed patient and family members from coast to coast to establish a Canadian network of champions for the first in-country PFPS workshop. Many of the champions were nominated by health regions or other healthcare organizations who see them as partners in improving patient safety. The outcomes of the workshop included the articulation of a set of five goals and a draft statement of expectations from the patient and family’s perspective on the disclosure process that is implemented when a patient has suffered harm or experienced a close call.
Directory of Organizations
A variety of organizations have been mentioned in the Guide. Please see below for a listing of their contact information.

**Agency for Healthcare Research and Quality (AHRQ)**
540 Gaither Road Rockville, MD 20850  USA
Phone: 301.427.1364
http://www.ahrq.gov/info/customer.htm

**Canadian Patient Safety Institute (CPSi)**
Suite 1414, 10235 - 101 Street
Edmonton, AB, Canada, T5J 3G1
Toll Free: 1.866.421.6933  /  Phone: 780.409.8090 /  Fax: 780.409.8098
info@cpsi-icsp.ca
http://www.patientsafetyinstitute.ca

**Consumers Advancing Patient Safety (CAPS)**
One W. Superior Street, Suite 2410
Chicago, IL 60610 USA
Phone: 312.274.1301 /  Fax: 312.274.9696
info@patientsafety.org.
http://www.patientsafety.org

**International Alliance of Patients’ Organizations**
703 The Chandlery
50 Westminster Bridge Road
London SE1 7QY, United Kingdom
Phone: +44.20.7721.7508 / Fax: +44.20.7721.7596
info@patientsorganizations.org
http://www.patientsorganizations.org

**Pan American Health Organization (PAHO)**
525 23rd St. NW
Washington, DC 20037 USA
Phone: 202.974.3000
http://www.paho.org/

**World Health Organization (WHO)**
World Alliance for Patient Safety
Patient Safety, Health System Policies and Operations (EIP/SPO),
Avenue Appia 20, 1211 Geneva 27, Switzerland
Phone: 41.22.791.21.11 / Fax: 41.22.791.3111
patientsafety@who.int.
http://www.who.int/patientsafety/en/
HOW TO USE THIS GUIDE

Consumers Advancing Patient Safety (CAPS) presents **Building the Future for Patient Safety. Developing Consumer Champions: A Workshop and Resource Guide** (The Guide) for readers with the intent that it will provide information and insight to empower individuals and organizations alike to develop effective programming for future leaders in the patient safety movement. Through this publication, CAPS wishes to share its experience with others that seek to develop and convene interactive, engaging workshops that involve patients, consumers and a variety of practitioners and professionals from healthcare and other industries to drive change for patient safety through education, networking and partnership. It is not intended as a step by step workbook, but more one that provides an introduction to a process along with context and insight from the collective experience of presenting the workshop model described.

CAPS hopes The Guide will foster creative conversation by readers and their meeting development teams. It is not intended as a tight framework to be rigidly adhered to. This publication provides resources for personal investigation and growth. We particularly envision that the Appreciative Inquiry process as discussed herein will be seen as a tool for a wide range of initiatives our readers undertake.

The audience for this publication is primarily individuals that have a basic knowledge of patient safety and are aware of the challenges in incorporating the patient voice in work to develop partnerships to drive improvements. CAPS assumes that the readers have some awareness of meeting planning and logistics but that they may not have experience in crafting sessions that focus on interactive work with participants that represent a variety of perspectives from within the healthcare industry as well as those representing consumer experience with its services. Readers are encouraged to refer to the endnotes and other resources to help fill gaps in their understanding of the concepts discussed and seek clarification as needed.

The Guide consists of the following sections:

**Part 1 - Workshop Process and Implementation**
This portion serves as an introduction to the process CAPS has employed successfully over the course of several years. This portion of the Guide will be most useful to individuals who are new to the primary structure to planning facilitated workshops and that are new to the concept of Appreciative Inquiry. It includes sections on the strategies to prepare for a workshop, a walkthrough with a suggested agenda and associated content, fundraising strategies and evaluation. In addition to the background that formed the CAPS process, Part 1 provides narrative describing the workshop practice and its use in the field drawing from CAPS sessions held between 2003 and 2006.

**Part 2 – Related Tools**
To supplement the narrative text describing the CAPS workshop process, documents and materials that were actively used to support the development and launch of these programs are included. They are being made available in full text in this section as appendices or are hyperlinked in context as appropriate. They will be noted in the text by the Appendix number. Additionally, many items in this collection of documents will be provided in Word in
the online version of the tool as a set of downloadable items that can be used directly by readers to minimize “reinventing the wheel.”

Definitions
CAPS understands the terms used in discussing patient safety work can be open to interpretation by a wide variety of individuals. It is recognized that their use of terms and labels directly reflects their experiences in shaping a role for themselves in improving the safety of healthcare. To help to clarify the language used in Building the Future for Patient Safety, the following definitions are provided.

Caregivers
Caregivers are family, friends, partners and neighbors that provide vital services to the chronically ill, elderly, and disabled.

Champions
Patient Safety Champions are a network of patients and consumers from around the world who are committed to patient safety. The Champions’ collective voice and passion to make a change in healthcare are expressed in the London Declaration (Appendix A). All Champions have gone through a facilitated workshop process.

Non-consumer stakeholders:
Non-consumer stakeholders are typically professionals from the field of healthcare or related areas of interest that demonstrate a commitment to through working in partnership with consumers to apply their expertise or engage their network to improve patient safety.

Patient / Consumer
The terms patient and consumer are used interchangeably throughout this Guide and refer to anyone who is receiving healthcare services.

Providers
Healthcare providers are physicians, nurses, pharmacists and others that provide healthcare services.
PART 1 – WORKSHOP PROCESS AND IMPLEMENTATION

PART 1 - SECTION I
WORKSHOP PRE-DESIGN

Why did CAPS choose Appreciative Inquiry? CAPS felt that in order to effectively create consumer change agents, a facilitation strategy that positions consumers as partners trained to work with clinicians, policymakers and others was in order. AI works to discover the best of “what is” in a community and uses that to energize the design and achievement of “what could be.”

Part of the shift that occurs in these workshops is the appreciation that providers can work with consumers on patient safety, not just for them. Including consumers from the very beginning – the discovery phase -- in this process yields a shared mental model of what could be that is, almost by definition, patient-centered.

What is Appreciative Inquiry?

Appreciative Inquiry (AI) is a group process methodology designed to use participants’ past personal and professional successes in addressing challenges and creating inspired, positive change. The AI methodology is rooted in social constructionism – the theory that human beings co-create reality through our language, thoughts, images and beliefs about what is. Change is energized, therefore, by the discovery of new thoughts, beliefs and language that shift current mental models about what is (eg, “patients who experience medical error are angry, potential litigants”) to what could be (eg, “patients who experience harm are a unique resource to continuous learning systems”).

AI was developed and pioneered at the Cleveland Clinic in 1980 by David Cooperrider, PhD, and associates as a new paradigm with the potential to replace the conventional problem-solving approaches to transformative learning. Problem solving group process attempts to analyze deficits, identify root causes and make corrections. It generally relies on crisis – a sentinel healthcare event, for example – to create a disorienting dilemma that motivates participants to critically self-examine and internally shift their mental models of what makes sense or what actions are desirable. A central challenge to problem-based approaches is strong resistance to the guilt, shame or disorientation that may attend such an experience.

Appreciative Inquiry shifts this focus to a desired future or outcome, based on strengths and passions that are apparent or have been experienced in the past and present. AI does not ignore problems, but recognizes and repositions them as a desire for something else, then works to identify and enhance that “something else.”
This positive change strategy is particularly well suited to challenges that require the formation of new and optimistic relationships. It offers a more constructive approach for consumers and providers working on safety issues who, in a problem-solving context, are likely to get bogged down in feelings or regrets about systems that failed and the people who were harmed.

The process enables consumers, providers and policymakers to generate fresh perceptions of one another, thereby allowing for the revitalization of the social bond and a heightened collective will to act. In its broadest focus, it involves systematic recovery of what gives “life” to a living system when it is most alive, most effective, and most constructively capable. In short, Appreciative Inquiry searches for and builds on the best in people, their organizations and the relevant world around them. By focusing on what’s right, rather than what’s wrong with an organization or community, AI fosters collaboration and energy that can be transformative.

**Questions and stories**

Appreciative Inquiry involves, in a central way, the art and practice of asking questions that strengthen a system’s capacity to apprehend, anticipate and heighten positive potential. According to AI theorists, the types of questions we ask determine the types of answers we receive and the direction in which the energy or enthusiasm of a group will flow. Hence, the “seeds of change” are implicit in the very first questions asked. The hallmark of AI is that these questions aim at soliciting positive experiences, stories and emotions from participants.\(^{12,15}\)

This can be challenging in the patient safety context, given the traumatic impact of medical error and negative feelings harbored by both consumers and healthcare professionals who have experienced system failure. This challenge is met by capturing stories which foster images of success, even if they arise from tragedy. Past tragedies are respected and lost loved ones are acknowledged and appreciated, but the focus is on what these painful experiences have produced that is positive and oriented toward the future. What was discovered during the experience? Where was there innovation? Who worked together and how did that happen? What was remedied?

AI methodology presumes that stories can be transformative in two ways. First, they have the potential to create a relatedness of experience that is then shaped by conversation among meeting participants into a path to future change as a community.\(^6\) Second, reflecting on the stories of others or responding to other’s questions about one’s own story can lead to internal reframing of what happened -- a shift of perspective that helps individuals move forward in a process of healing or overcoming their own resistance to change. In other words, the AI process inspires change at both the group level and for the individuals participating in the group.\(^12\)
What Guides the Work?
Four principles guide the AI process:

1. Every system works to some degree; seek out the positive, life-giving forces and 
appreciate the "best of what is."
2. Knowledge generated by the inquiry should be applicable; look at what is possible 
and relevant.
3. Systems are capable of becoming more than they are, and they can learn how to 
guide their own evolution – so consider provocative challenges & big, bold dreams of 
"what might be."
4. The process and outcome of the inquiry are interrelated and inseparable, so make 
the process a collaborative one. 15

It should also be noted that there is a formal structure to the AI methodology, known as the 
"4 D Cycle," which is:

- Discovery -- Appreciating & Valuing the Best of "What Is"
- Dream -- Envisioning "What Might Be"
- Design -- Dialoguing "What Should Be"
- Destiny -- Innovating "What Will Be" 15

Our workshop designs typically incorporate all elements, but not necessarily as distinct 
blocks of agenda time. Accordingly, our use of AI may be best considered a variation on the 
formal structure of the methodology.

How to set Workshop Goals and Agendas

CAPS begins its workshop development process with the establishment of a planning group 
who meets by phone or in person. In developing our workshops, we were faced with a 
reality that most patient safety gatherings that include consumers are not designed by them. 
Indeed, consumers frequently find themselves invited into programs that have been 
developed without recognizing their point of view and embedding it in the content, process 
or proceedings. If consumers are included at all, it is often in a way that doesn't fully 
appreciate their role.

Accordingly, CAPS turns this approach on its head. Our goal is to design a workshop that 
truly is consumer led and centered, and thus not over-designed or controlled by providers or 
consultants. We start with recruiting a person who self-identifies primarily as a consumer as 
the chair or co-chair. This is the first step in ensuring that the planning effort will be patient-
centered. Other planning group members should include clinicians, healthcare organization 
leaders, policymakers or other stakeholders in the community. Event facilitators and logistics 
coordinators also should be included. This group should be kept to 10 people or less.

Once the workshop planning group is in place and acquainted with one another, a first task 
for them is to determine the number and composition of participants. CAPS has facilitated 
workshops that focused on (1) events for consumer participants only, and (2) programming 
for mixed groups of consumers, care providers, organizational executives, policymakers and 
other stakeholders. Both have been successful, although in consumer only workshops it is
crucial to build into the agenda the opportunity to interact with non-consumers healthcare stakeholders. To date, CAPS has worked with as few as 20 participants and as many as 50. The workshops have typically been organized as 2 to 4 day events.

Goals are developed by the planning group. Agendas and meeting logistics are planned with care. But goals and agenda are designed to be re-negotiated with participants as the workshop unfolds. Specific times are set forth in the agenda, generally at the beginning of each day, to consider shifts in emphasis or structure.

Two kinds of goals should be set by the planning committee, objective and subjective. Objective goals are the focus areas or topics of interest. Objective goals can extend to vision or mission development, strategic planning, policy development, the implementation of plans or even the articulation of values that will guide a group. Examples of objective goals developed for patient safety workshops CAPS has facilitated include:

- To build a foundation for a movement that empowers consumers with a collective voice to address healthcare with safety for all is the first consideration
- To envision the roles through which consumers can help keep healthcare honest and transparent
- To identify practical steps and pathways for consumers to partner in improving the safety of their healthcare
- To nurture the passion and commitment that will sustain enduring efforts to improve safety and prevent medical error
- To show stakeholders throughout healthcare that patients and their advocates are an important resource for improving healthcare
- To help imbed the principles of patient safety and patient-centeredness into the culture of healthcare organizations
- To create public recognition of the opportunities for their involvement in ensuring safe care
- To show how the power of disclosure and forgiveness can create healthy change for patients, families and providers with positive benefits for healthcare systems

The subjective goals are subtler, but arguably more important. They are focused on process, climate and community. Examples include.

- To build trust and relationships
- To appreciate, value and respect each other’s differences
- To shift orientation from problem-oriented to possibility-focused
- To renew group energy, hope, motivation and commitment
- To establish a climate of continual learning and inquiry
- To seek improvement through respectful conflict resolution
- To help those who have directly experienced medical error, whether consumer or provider, to heal

In developing subjective goals, CAPS and its partners have often used a workshop metaphor that expresses the aspirations of members of the planning group. For example, we agreed upon a campfire as the central metaphor for the Houston workshop which established Consumers Advancing Patient Safety, imagining that consumers who had experienced medical error would initiate the gathering by telling stories about who they were
“around the fire, under the night sky.” In the London Workshop, we employed the metaphor of building the foundation of a house, a safe place for us and for our invited guests to meet and converse. Other metaphors being considered include the unburying of the “treasure” of the experience workshop participants brought to the community.

**What are the agenda planning tools?**

The goals of the workshops have driven the content of the agenda for each event. We have used various agenda development tools to help shape the workshops. We have borrowed from the field what we have found to be effective and repurposed ideas from the toolkits of others.

A good source of practical advice and examples where AI has been used can be found at Appreciative Inquiry Commons ([http://appreciativeinquiry.case.edu](http://appreciativeinquiry.case.edu)), which has an extensive practice and management resource section that includes draft workshop agendas. Many resources at this cite can be downloaded for free.

Other good tools – for both facilitators with little experience and those who want to freshen their acts – are available for purchase from The Grove Consultants International ([http://www.grove.com](http://www.grove.com)). The Grove’s basic four step OARRs (Outcomes, Agenda, Roles and Rules) Model has been part of the architecture of every workshop we have designed:

1. List desired outcomes in advance or draw them from the group
2. Identify possible activities and sequence them in general time blocks to make a graphic agenda
3. Agree on roles
4. Review general rules—ask “What will contribute to a successful meeting?”

The OARRS model is explained on page 24 of The Grove’s, *Best Practices for Facilitation*. This basic text, together with *Principles for Facilitation*, both by David Sibbet, can be used by anybody and are well worth the purchase price.

We also have included a sample meeting agenda as [Appendix B](#) to this toolkit, to be used as a springboard for your patient safety workshop development process. It will be used as an example throughout The Guide.

**What about logistics planning?**

While logistics planning is beyond the scope of this guide, we cannot emphasize enough the role of an experienced meeting planner as part of your planning group. Consumers involved in CAPS workshops sometimes have had special needs or were unacquainted with the basics of professional medical/healthcare meetings, therefore needing some extra attention in planning/managing travel. We include the meeting planner in substantive planning meetings, not just those dealing with logistics, and often turn to them for advice on how logistics can help us achieve both our objective and subjective meeting goals.

Our workshops have been planned in as little as four months, but a development timeframe of at least six months is suggested if at all possible. Please see Appendix C for a timeline template that will identify a time frame for planning an initiative.
Who Do We Involve -- A Call for Participants

In the development of a workshop, the collaborative inquiry as part of the AI process starts with pre-workshop questioning that can be easily embedded in the participant application process. If timing permits, it can be further developed through a pre-workshop interviewing effort.

Generally, we have begun with an open call for applicants accompanied by a widely disseminated application form which was distributed via the press or existing networks such as emailing an announcement to partnering organizations or use of their membership contact databases. The call announces that we are seeking:

1. Consumers interested in partnering to make healthcare safer, who had substantially interacted with healthcare and saw themselves as a change agents; and if this is a mixed stakeholder event,

2. Non-consumer healthcare stakeholders interested in partnering with consumers to establish safer and more patient-centered care.

Examples of the CAPS Call for Participation and the nomination and application form used for the Vancouver workshop are included as appendices D and E. In the attached documents, you will see that the call for participants provides further context as appropriate.

Our strategy was to encourage applications from individuals who were seen to be seen as change agents, who were consumers of healthcare or who worked or participated in any healthcare setting, including acute, ambulatory, long-term and home-based care.

Consistent with the AI approach, applicants were asked to submit applications that respond to a few basic questions to prompt reflection about past professional or personal experiences which produced success, involved partnering and led to innovative solutions. A fourth question invites the applicant to tell us more about what he or she has to share regarding patient safety and their commitment to making a difference. Questions have been adjusted from event to event, but the basic template is as follows:

1. Describe a time when you were involved in making healthcare really work for you or somebody you know. What made it work? [Success Question]

2. In what ways did others (the patient, their family or friends, healthcare providers or others) partner in making it work? Please describe how you and the others figured out how to do what you did. [Partnering Question]

3. Describe an experience where you have succeeded in changing something or accomplished a goal by overcoming obstacles in an inventive way. This can be a healthcare experience, but doesn’t have to be. [Innovation Question]
4. What do you expect to share and contribute at the workshop?[Commitment Question]

Each application was reviewed by each member of the Planning Committee, who then discussed them in person. Selections were made by consensus vote of planning group members. In the few cases where we could not reach consensus, majority vote prevailed.

Is There Workshop Prework?

Once applicants are selected, we recommend pre-work before the Workshop begins. This includes reviewing orientation materials sent out in advance. If time permits, we also recommend setting up and coordinating telephone interviews between participants who don’t know each other. This process involves using an interview guide built on Appreciative Inquiry-centered questions (An example is included as Appendix F). Interview reports are then returned to and reviewed by facilitators before the workshop. Essentially this becomes Participant A retelling the story of Participant B.

As noted earlier, stories are central to the AI process not just for the lessons that might be learned about a particular systems failure or experience, but because of the images of success they foster. In our work, the benefits of the interviewing process were manifold:

- First, it generated optimism by helping participants discover the positive possibilities that their interview partners could amplify through the AI interview.
- Second, it helped form relationships that would create the basis for building partnerships in the workshop. This has worked well in helping consumers and providers find common ground, which is almost always the experience of being a consumer.
- Third, the interviews help participants practice listening respectfully and seeing beyond their own story.

The story telling portion of the event will benefit from setting some expectation of the workshop invitees up front. It is important to discuss with each person ahead of time the time they’d like to present their stories. Another successful tactic is to ask each person if they would like to do a full presentation on their efforts and try and facilitate an opportunity to do that outside of the planned meeting itinerary as appropriate. Evaluations showed that workshop participants were generally positive about the AI interview, but in terms of building a foundation for the partnership that was formed during the workshop, Appreciative Inquiry proved to be a critical method. We have included more on the evaluation process later in the text.

How to use visuals effectively?

Another pre-workshop request we have made is to invite selected participants to bring a picture of a loved one who has experienced medical error and may not be able to speak for themselves. These photographs would then be posted as a powerful visual and memory aid throughout the workshop event about the importance of the work at hand.
If the budget permits, we recommend retaining a photographer to capture the meeting in candid photographs that become part of the story of the meeting. Often, photographer services have been donated as an in kind contribution of a workshop supporter. Images of collaboration between consumers and providers have helped us capture and convey the energy of consumer/provider collaboration in communication activities after the event, both to workshop participants and external audiences. If you decide to develop this aspect of your meeting, it is important that an image of every participant be captured. Nobody should be left out.

**How do facilitators prepare for the event?**
The primary objective role of the facilitator is to keep the ball rolling enough to accomplish the objective meeting goals. But facilitators also are chiefly responsible for nurturing the creation of an environment which feels respectful and safe. We prefer using very skilled facilitators for these workshops. We have done workshops using single facilitators, but recommend using a team of two who work well together. Facilitators are always included in our agenda planning and applicant selection activities.

In preparation for the workshop, it is important that facilitators anticipate:

- that participants will want or need to share very personal experiences and express a range of feelings, including grief, anger and frustration;
- a range of personalities, including people who are eager to talk from the get go as well as those who may need to be coaxed;
- having to depart from the agenda from time to time to accommodate the energy of the group or the needs of individuals;
- having to make some hard decisions about who gets airtime and when; and
- having to intervene to stop behaviors that are damaging to the group dynamic, such as personal attacks or longwinded speeches.

In addition to lead facilitators, we often recruit other members of the planning committee or even selected meeting participants to facilitate small groups of specific workshop sessions. These are great opportunities for people interested in facilitation to build skills.

**A word about facilitators…**
As with all facilitation work, results are dependent upon experience, attunement with co-facilitators and basic listening and communication skills. Effective Appreciative Inquiry practice is built upon a solid foundation of authentic values like inclusiveness, integrity, developing trusting relationships, courage in challenging the status quo when needed, collaboration and negotiating effectively. While we prefer to use professionals when budget permits (or we can prevail upon them to donate their time), the truth is that anyone gets better by jumping in and doing.
The CAPS Statement of Principles, Values and Beliefs [Appendix G] serves as our “north star,” guiding all we do. In addition, the following practice tips should be useful to anyone thinking of using an AI approach:

- Begin with yourself. Practice being appreciative of yourself and others. Catch people doing something right and acknowledge them for it.
- Read something about AI and its foundations and applications (Appendix H).
- Practice crafting appreciative questions.
- Try some AI interviews with your co-workers and family.
- Begin meetings with appreciative questions like “describe something that you/we did really well this week, something that made you excited and proud of our work together. What made that possible? What can we learn from this?”
- Encourage your friends or clients’ (and your own) sense of adventure and innovation. Help them understand that no one really knows precisely where this (or any other real change process) will lead.

Fundraising

How to get started

One of the challenges for consumer initiatives in health care is the lack of reliable or mainstream funding; therefore workshop organizers may need to fundraise to achieve their goals. Fundraising for consumer involvement in patient safety is challenging, because it is not something that has been historically supported. Planners for many patient safety meetings can safely assume that participants will have some aspect of patient safety in their job descriptions. They may have organizational budgets to turn to for expenses, perhaps even a registration fee. These assumptions cannot be made for consumers who have an interest in patient safety. Participation in a workshop usually will not be covered by another organization’s budget. Moreover consumer travel may require missing work or paying additional expenses such as child care for days away from home.

But these challenges make fundraising for consumer involvement rewarding as well. Asking for support for consumers is easy to explain and has not been overdone. People who enjoy fundraising are likely to find that most people will quickly get why this work is important. Given survey data suggesting that over 40 percent of Americans have experienced medical error either directly or through a family member or close friend, many people with funds to contribute may themselves have personal experience that will help engage their interest. 7, 8.

It should also be remembered that fundraising has collateral benefits. Done well, it can serve to gather grass roots and broader community support, foster awareness for the cause, gain free publicity and facilitate networking with like minded advocates and change agents.

We recommend that the workshop planning group include at least one or two persons with some experience with fundraising. Other group members can be encouraged to approach it as a learning experience. We suggest that they refer to the annotated Fundraising 101 slide set and the “Grant Writing/Fundraising” resource area on the CAPS web site for introductory information on fundraising.
Consumers Advancing Patient Safety has learned that fundraising takes time and serious planning to be successful.

- Research on possible donors, foundations and private citizens to approach is imperative.
- Think “outside of the box” when identifying potential sources of funds. Often money goes unused each year because no one applies for it.
- Plan the event carefully, with a budget and clear objectives. See Appendix 1 for a sample budget template.
- Make sure to allow enough time for each portion of the preparation and for possible delays in receiving funds once they are awarded.
- Adjust spontaneously.
- Never underestimate the importance of a nurtured network of like-minded individuals in facilitating access to funds.
- Learn from the experience.

CAPS and its partners have employed several strategies to help cover the basic costs of its workshops and other events:

- Scholarship sponsorship and grants: Small donations (@$3,000) to cover the expenses of individual consumer participants can appeal both to individuals and corporations
- Government grants: both AHRQ and the Regional office of the US National Library of Medicine have provided support for programs CAPS has held or participated in.
- In-kind support
- Waived or discounted fees/expenses
- Volunteerism

Below we will outline several approaches that have been successful for raising funds to support the consumer workshops we facilitate.

**How to get funding for consumer participation**

As noted above, healthcare consumers often do not have employers that will cover their participation in patient safety meetings. Attendance at such events often entails taking vacation days from work or paying out of pocket to cover travel, meal and accommodation costs. These expenses can become obstacles to greater consumer participation in work to improve patient safety.

In order to mobilize consumer participation, CAPS invited interested organizations to provide scholarships to cover the costs of consumer participants in the San Francisco and Vancouver events (see Appendix 3 for a sample letter of invitation to join the planning group) and consumer scholarship opportunities. Each scholarship was used to cover the costs of a participant, for example, air travel, local transportation, meals and other pre-approved expenses.

Attendance for front line practitioners can also be problematic. Training budgets have been slashed in recent years, and participation in meetings where continuing education units (CEUs) are not given may not be covered. Every effort should be exercised to keep costs down in case these dedicated people also need to finance their own participation in the workshop events.
Who to approach
Scoping out potential funders can be started by thinking about these questions:

- Which organizations would benefit from this project?
- Which organizations have members who would benefit from this project?
- Which organizations or persons will want to participate or can help us identify participants?

These questions will help the planning group identify stakeholders and potential sponsors. Reach out to a wide field, with a persuasive “ask” and follow up plan. This puts you in a position to “get lucky.”

What about the ask?
In CAPS’ experience, the fundraising “ask” always incorporates a persuasive case statement designed to explain to potential donors why they should support this workshop initiative (see Appendix K for a Statement of Case). Key elements include:

- **Background:** Generally a description of the patient safety movement with some key features highlighted that pertain to the goals and objectives of the event

- **Need:** A description of deficits that stand in the way of consumer involvement or consumer/provider/policymaker partnership

- **Objectives:** These should track the goals set forth in the agenda, either in detail or overview

- **Timeline:** Basically, your plan from beginning to completion of deliverables

- **People:** This section should describe the kind of participants you intend to invite

- **Outcomes:** It is important that you think through your event well enough to identify specific deliverables such as a policy, a program, an action plan, or a mission

- **Role of Sponsors:** This section should outline for sponsors the roles they can play as participants, nominators of participants, planners or advisors. It should also explain how they will be publicly acknowledged/thanked, outlining different funding levels if you have them.

It’s very important to appropriately acknowledge and thank the sponsors for their support (See Appendix L and Appendix M for examples used in CAPS programs). Include the sponsoring organization’s logos in all workshop materials, communications and websites.

Once development and meeting funds are in hand, the participants selected and prepped, the agenda formed and the logistics in place, it is time to roll the program out. The next section shares the CAPS model of a workshop drawing from four workshops in which they have applied and refined their method.
PART 1 SECTION II
WORKSHOP EVENT

How is the Session Structured?

The Appreciative Inquiry approach has been used by CAPS to structure a number of other patient safety events since its formation. Outcomes have included:

- Formation of CAPS
- Launch of the World Health Organization’s Patients for Patient Safety (PFPS) Initiative
- The London Declaration (Pledge of Consumer Partnership)
- Development of CAPS Statement of Principles, Values and Beliefs (see Appendix G)
- Establishment of a consumer network in the Americas
- Development of a series of products to be developed by the group to disseminate its collective work (see Appendix N)
- Development of an initial action plan for the Eastern Mediterranean Regional Office (EMRO) of WHO

Although agendas varied from event to event, the structure of the process generally is as follows:

- Selecting a focus area or topic(s) of interest
- Using AI questions designed to discover strengths, passions and the “best of what is” (mapping to the Discovery phase of the 4D AI cycle)
- Identifying patterns, themes and/or intriguing possibilities and crafting these into bold propositions of “what could be” (mapping to the Dream phase of the 4D cycle)
- Co-determining “what should be” through a process of envisioning, mission articulation or the development of goals, principles or priorities for “what should be” (mapping to the Design phase of the 4D cycle)
- Prioritizing and action planning to achieve “what will be” (mapping to the Destiny phase of the 4D cycle)

These elements have been successfully woven into a 2-day session format under the sample agenda structure provided in this guide as Appendix B and is illustrated below.

How Does it Work? An Example of the Appreciative Inquiry Workshop Process

Every workshop is different. The best way to understand the process is to experience it. With that said, what follows is an outline of an adapted AI approach to engaging a community of consumers and providers in collaborative patient safety work.

Module 1 – Welcome and Logistics
This module is straightforward. We recommend that participants be welcomed by consumer leaders. Meeting supporters should be thanked. Facilitators should be introduced. Objectives, Agenda, Roles and Rules (the OARRs model) should be covered emphasizing the importance of trust and respect, and questions should be taken. We ask participants to
approve the agenda to help us hold them to it later on. Participants should be reminded that they will be working hard over the course of the event.

**Module 2 – Overview and Orientation to Topics**

Consumers will probably need orientation to the patient safety movement, if not to the basics of seeing patient safety through the lens of human error and systems approaches to improvement. See [Appendix C](#) for a readings list to acquaint individuals that might be new to safety with an introduction to some basic concepts. In addition, The Partnering for Patient Empowerment through Community Education and Awareness program, in which CAPS was a partner, has developed an [introductory slide set](#) template with notes as a model presentation to those new to patient safety and concepts of human error and safety science. See [http://www.galter.northwestern.edu/ppeca/](http://www.galter.northwestern.edu/ppeca/) for more information.

At this point in the session sponsoring organizations may want the opportunity to welcome or issue a request for assistance. The goal of this portion of the workshop is to provide context. Keep in mind that attending workshops like this might be a completely new experience for some consumers. And working with consumers in an intimate setting like this might be unusual for healthcare professionals as well. Watch for signs of discomfort, and remember that several participants will be wondering how much to trust the process or the facilitators at this juncture.

**Module 3 – Questions and Stories**

If you did pre-workshop interviews, there may already have been considerable pre-work done to build relationships between participants. But it still serves a valuable purpose for attendees to the workshop to introduce themselves and briefly share their stories. Alternatively, we have had the pre-workshop interviewer introduce the person he or she interviewed, and that has worked well. Staff and facilitators should also be included in this exchange. Facilitators should be acutely aware of the personal nature of this portion of the event. Individuals understandably can become angry and emotional. If they aren’t accustomed to speaking about their experiences yet, they may utilize more time than the meeting planners have allocated for this portion of the day. While it is important to respectfully allow for sharing during this section, facilitators need to be prepared to intervene if a story is disrespectfully long. This conveys the importance for everyone to take responsibility for respecting the time frame and structure of the event they are here to make successful. It helps to articulate the need to keep to a time schedule verbally to develop a shared mental model on the need to keep the initial story presentations within the time limits so everyone present has an appropriate opportunity to share.

"The stories of others clearly showed that my wife’s tragedy was not simply an isolated, unfortunate incident."

Vancouver Workshop participant

October 2006

This session initiates the *Discovery* phase of the AI process at the workshop. The objective goal here is to appreciate and value the best of what is in the experience of participants. It is important to capture the insights that emerge from participant stories on paper or graphic pictures. This can be done through asking participants to share or, if paired interviews were
done, asking participants to share the experience of the person they interviewed. Rich content is invariably produced. This process should not be hurried. Depending on the number of participants, it can take several hours. Some people will speak up sooner than others. The subjective goal of this phase is to foster an atmosphere of trust, respect and collaboration.

**Module 4 – Big Hairy, Audacious Dreams**
Typically a break, such as a meal, is taken between the Discovery phase and the Dream phase of the AI process, which should be fed by the insights and images produced earlier. The focus of the Dream cycle is “what might be” and it is typically launched by another inquiry, such as:

> If you could transform healthcare in any way you wish, what would it look like in 20 years and which three things would you change first?

CAPS has had success in asking people to use the device of a letter to the future, written by them on the hypothetical eve of their retirement from their life’s work to a trusted successor, about the things that had been accomplished and the meaning of these accomplishments. These letters are then gathered and digested by a small group of volunteers, who use the content to develop a concept of the future.

In the Houston workshop, volunteers worked late into the night, returning to the group in the morning to start Module 5.

**Module 5: Articulating the Dream**
Building on the languages and images shaped in Modules 3 and 4, the Founding Advisors of CAPS started Day 2 by reviewing and refining the following draft statement synthesized from their letters to the future:

> We are the lifeline for patients, their families and healers who suffer medical error. We are the consumer advocates who find and partner with healthcare leaders to form communities of concern for excellence and for the person in healthcare. Together we make safety come forth from the expectation that we the consumers set for healthcare that is compassionate, safe and honest. Our National Healthcare Safety Board oversees the error reporting system and assures that medical licensure depends on learning from medical error. Our local Citizen Advisory Boards are partners with those facilities that support healing and restore hope, making them the places where patients want to go. We work with the medical schools to teach the written and unwritten rules that go with you when you are sick. We will not go away. We are the lifeline.

During this module, several people who had been quiet the night before became active. Creative energy was flowing.
Module 6: Training or Guest Speaker & Module 7: The Fishbowl
These are optional modules that we have used when the participant group has been weighed heavily with consumers. It provides the opportunity for consumers to obtain new skills or to meet thought leaders in the patient safety community. It also provides the reciprocal opportunity for leaders to get feedback and hear the wisdom of the patient. They are never dull and we have witnessed interchanges between speaker/panelist and consumer participants get heated. Facilitators have to be prepared to intervene. With that said, these are most often enormously rewarding experiences for “both sides.”

Module 8: Goal Setting
Participants are typically energized by what had been created during the Dream phase of the workshop, even if they didn’t completely agree with it! This energy fuels the Design phase, the focus of which is “what should be.” We like to use both large and small group exercises to generate work product. During the Houston Workshop, this process involved distilling the Module 5 Dream statement presented above into articulations of vision, mission and goals:

**VISION**

We envision a partnership between consumers and providers to create global healthcare systems that are safe, compassionate and just.

**MISSION**

- **To be a champion** for patient safety in a new healthcare culture.
- **To be a voice** for individuals, families and healers who wish to prevent harm in healthcare encounters.
- **To teach** the health care community what consumers and providers need to know whenever they interact within healthcare systems.

**GOALS**

- **Goal #1**: Establish national consumer-led patient safety boards
- **Goal #2**: Create local consumer-led patient safety advisory boards in every community
- **Goal #3**: Institute non-punitive national patient safety learning/reporting systems
- **Goal #4**: Establish an education effort on patient safety for providers and consumers
- **Goal #5**: Develop a patient safety awareness campaign that emphasizes patient and healthcare community partnership with trust and open communication
- **Goal #6**: Put into place systems that provide just compensation and alternative routes to justice for patients who are harmed in interactions with the healthcare community
This example illustrates the richness of content that can be generated during the AI process. It is thought work that is both inspiring and taxing, and participants will react differently. Meeting planners need to build in breaks. Participants may give facilitators feedback about working too hard. If that happens, it helps to have warned people during the early modules.

**Module 9: What will Be**
The *Destiny* cycle (innovating “what will be”) was a half day of programming that rolled out largely through small group work facilitated by volunteer moderators. Essentially this was strategic planning focused on identifying resources, knowledge gaps, interim milestones, timelines and participant commitment to future actions.

**Module #10: Wrap-up**
During this final portion of the event the products developed during the workshop should be finalized and next steps outlined. Workshop participants make personal commitments to carry forward the work started during the workshop process. This session ends with an opportunity for every participant to share thoughts about what they have experienced and about the future of patient safety and to celebrate what has been accomplished.

Once a workshop has been held, the AI process complete, it is envisioned that the stage has been set for a new, consumer-led initiative to be launched. As mentioned above, CAPS has facilitated the development of several initiatives that are currently thriving on the international patient safety stage. Readers can visit [http://www.patientsafety.org](http://www.patientsafety.org) for the latest information on current CAPS programs.

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**Workshop Picture placeholder:**
perhaps one of the group shots taken at the end of the event of everyone who attended a workshop would work well here.
PART 1 SECTION III:  
WORKSHOP EVALUATION AND PARTNER RECOGNITION

Why Evaluate?

Program evaluation involves collecting information to make decisions about improving the program. Program evaluation is not about proving success or failure, but it is essential to making adjustments for improvement by remaining open to continuous feedback. Evaluation is a way to measure whether you achieved your program goals and objectives. Based on responses, the content, location, speakers or agenda may need to be adjusted so that the program meets its goals and objectives.

It is also important to engage the participants in future events that will be supporting the issue they have come together to fix. Giving them the opportunity to weigh in on the proceedings and future activities will allow them to feel more important and will facilitate the meeting planners learning from their attendees. It is important to follow up and act on what is learned, otherwise the promises can be seen as empty and insincere, which is not a feeling you want individuals who are being recruited to drive change in patient safety to feel.

Lastly, evaluations are effective tools for communicating the success of your program with funders and other organizations.

What Do You Measure?

It often helps to think of your programs in terms of inputs, process, outputs and outcomes. Inputs are the various resources needed to run the program, for example, money, facilities, participants and program staff. Process evaluation is how the program is carried out and the success of putting the workshop or program together. Questions may include:

- Was the size of the room appropriate?
- Were the speakers good?
- Were the handouts useful?
- Was the length of time for the program appropriate?

“The session gave me the sense that this is the beginning of something important and that we can all play a part in moving it forward.”

San Francisco  
Workshop participant.  
May 2006
Outcomes evaluation attempts to determine whether the participants learned from the program and if they will use and disseminate the information. Outcomes are the impacts on the targeted population. Questions may include:

- How will you use the information you learned?
- How will you use the energy/passion/aspirations and vision articulated during the course of the workshop in your work?
- List the three most important points you learned.

**How do you gather the information you need?**

- Evaluation forms should typically be short. See Appendix F for a sample form.
- They should facilitate both quantitative and qualitative responses.
- They should allow for follow up from the meeting planners.

Survey capabilities on the web can also be utilized. The strategy of asking participants to share their thoughts after they have been home and rested from a powerful educational event may work well for this audience, especially if they are comfortable with technology.

Email communications can also be used to continue a conversation with your participants and help get them into the loop of disseminating announcements and other information about your organization after the meeting is over. Care should be taken when utilizing email as a distribution and communications tool. Always ask if you can use their email address, and give each participant the opportunity to opt out of email distributions.

**What has CAPS Learned from its Evaluation Process?**

"Unquestionably the simultaneous translation of ideas was a major contributing factor to the success of our workshop."

San Francisco Workshop participant.
May 2006

Most consumer participants in the workshops we have facilitated describe the events as having been an important experience in their lives. Many have reported a change in the way they think about medical error or a deeper understanding of the issue as a result of their participation. Most indicate at workshop end their willingness or intention to stay involved or become more involved in patient safety activities. Post-workshop networking has been very active via email, and we are witnessing the emergence of an international network that is exciting to see.

Health professional participants in the workshops we have facilitated have indicated that the event got them to identify as healthcare consumers – we all are, after all – more than they had in the past. Post-workshop we have seen several consumer participants be invited by provider participants to play new roles as consumer advocates or spokespersons. We believe this to be indicative of trust having been generated, but it probably also is fair to say that these events help providers observe and select those consumers they feel have the most to offer.
Products produced during the workshop have also received positive attention. The vision statement produced by the Houston workshop – to create healthcare that is safe, compassionate and just – resonates widely. Our mission, goals, principles and beliefs appear to have enduring relevance.

Another product, the London Declaration [Appendix A] produced during the London Workshop in 2005 is widely quoted and acclaimed for its authentic pledge of partnership. Appendix N shares a collection of products developed by the Canadian champions during the Vancouver session. In addition, a slide set was generated from work at the Vancouver session to help new patient safety initiatives measure and evaluate their progress.

**How Can You Recognize Those who Helped make it Happen?**

Sponsors were recognized in all communications that went out about the workshop events (see Appendix M as an example) and were listed on the convening partner’s websites. Post event, sponsors were sent thank you letters (see Appendix L) along with a DVD of photographs and video footage from the workshops. Sponsoring organizations were invited to have a representative sit on an open dialogue Q&A panel during the workshop and interact with the participants. The photographs and video footage captured during the workshops are an effective mechanism for capturing the humanism of the events.

**Epilogue: What is the Future for this Concept?**

This guide is intended to help develop the role of consumer as partners in healthcare by supporting other workshop efforts globally. We invite comments and feedback on the usefulness of the guide and your application of the workshop model in your efforts to help develop the collective voice of partner-oriented consumers. Share what you’ve learned with others through the CAPS online communities at [http://www.patientsafety.org/](http://www.patientsafety.org/).

CAPS thanks all of our supporters and contributors to this project, especially the US Agency for Healthcare Research and Quality. Without their support our work would not be possible.

“*It feels just like a door has been opened. Hopefully we will stay connected and build together.*”

Vancouver Workshop Participant, October 2006
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