

Patient-professional partnership examples, best practices and recommendations

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Patient-Professional Partnership
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I. Introduction

Health care systems around the world are moving quickly to improve health and become financially sustainable as they brace themselves to meet increasingly complex needs. Ambitious health care visions like the [IHI's Triple Aim](#) for global improvement, the [IOM's recommendations for a STEEP model of care](#) in the US, and [God Vård](#) in Sweden propose sweeping structural reform to create a system of care that is integrated, effective, safe, equitable, cost effective and person centered.

While technology and research are enabling significant health breakthroughs, health care has begun to realize that patients are also enabling improvements by participating in the creation of their own care and health care systems. The message that engaged patients have the potential to be "the blockbuster drug of the century"¹ has been the subject of countless conferences and articles in recent years and has reached a tipping point among forward-thinking professionals and patients globally and in Sweden.²

Patients, too, want to reclaim their active role in their own health and leverage breakthroughs in research and scientific advancement. Social networks and technology are facilitating a fast-growing movement in self-care and patient empowerment, and traditional patient advocacy organizations are being asked to collaborate in new ways.

The purpose of this report

This report together with an accompanying workshop aims to aide QRC in strengthening patient-professional partnership internally and to inspire and encourage the Swedish health care system's shift toward increased partnership in health overall. Portions of this document will be used to create a public report that will:

- describe the current state of patient-professional partnership
- provide examples of cutting-edge partnership
- suggest trends in patient-professional partnership and a tool that QRC can use to assess their own progress
- propose new competencies and resources needed for health care, providers and patients generally, and for QRC specifically

A select list of toolkits and guides regarding patient-professional partnership is included at the end of this report.

II. Patient-Professional Partnership: Definitions and a Framework

Until now, the phrase "patient engagement" has been a catch-all term to describe an activity in which patients and professionals partner in non-traditional ways, specifically the participation of patients in their own care and the creation and production of care systems. It could describe anything from shared-decision making, patient & family advisory councils or simply a suggestion box in a clinic waiting room. As this type of collaborative work evolves, there is a need for more precise terminology and conceptual models if we wish to cultivate and evaluate it.

¹ <http://www.hl7standards.com/blog/2012/08/28/drug-of-the-century/>

² For example, *Patienter och personal utvecklar vården*. Sveriges Kommuner och Landsting, 2011.

What do we call it?

In the past year or two, the phrase *patient engagement* has become problematic. Along with others such as *patient involvement*, *patient activation* and *patient compliance*, or the Swedish phrases *patientmedverkan* and *patientinflytande*, it can be seen as the product of a paradigm in which the health care system is at the center of health, inviting patients to affect change on it to varying degrees when it suits their needs. As we will see, this paradigm no longer accurately describes the spirit or reality of what forward-thinking patients and professionals are attempting to achieve by collaborating in radically new ways.

We believe the phrase *patient-professional partnership* more accurately describes the nature of this new type of collaboration and therefore propose its use. It implies reciprocity and equality for all stakeholder groups, most importantly the sharing of the *formulation privilege*, i.e. the implicit right to form agendas, ask questions and initiate efforts. It also recognizes that everyone will need training and support to learn to work together, even if patients will always have a special status as end-users of the system.

What is it? A Framework for Patient-Professional Partnership

In order to discuss and assess patient-professional partnership in more detail, we propose the following Framework for Patient-Professional Partnership (see Figure 1). This framework can be a helpful tool in assessing QRC's (or any organization's) progress or identifying opportunities for partnership. It was adapted and enhanced from the work of Carmen et al's "Multidimensional Framework for Patient and Family Engagement in Health and Health Care".³

The Framework for Patient-Professional Partnership includes three factors:

- 1) **Place**, the level in which the partnership occurs within an ecological context
- 2) **Phase**, the phase of a project life cycle in which collaboration begins
- 3) **Parity**, the degree of reciprocity present in the partnership.

The first two spectrums, Place and Phase, are the axes for a matrix. The third factor, Parity, represent values that are not plotted within the matrix but can form the basis for reflection and dialogue as patients and professionals enter into partnership activities.

Partnership is considered to be more robust if the activities span across levels and phases. Typical partnership activities in much of health care today, for example, focus almost exclusively on the evaluation phase, in the form of surveys, suggestion boxes, or even patient safety reporting platforms such as Sweden's Lex Maria. It is only after the service has been delivered that patients are asked to weigh in as individuals. Another example of more common patient participation is the advisory board (*patientråd* or *referensgrupp*), but these groups inconsistently participate in the planning or implementation of design projects.

³ A Multi-Dimensional Framework For Patient and Family Engagement in Health and Healthcare. Carmen K L et al. Health Aff 2013; 32:22.

		<i>Phase</i>			
		<i>Design</i>	<i>Plan</i>	<i>Implement</i>	<i>Evaluate</i>
<i>Place</i>	<i>Direct care</i>	<ul style="list-style-type: none"> • Person-centered care 	<ul style="list-style-type: none"> • Patients' values and culture incorporated 	<ul style="list-style-type: none"> • Using decision aids together 	<ul style="list-style-type: none"> • Surveys, suggestion boxes • Safety reporting systems
	<i>Clinic</i>	<ul style="list-style-type: none"> • Identify and prioritize improvement needs together • Service design approaches 	<ul style="list-style-type: none"> • Redesign the focus of the clinic visit together 	<ul style="list-style-type: none"> • Patients on clinical improvement teams • Patients as coaches, coordinators, staff 	<ul style="list-style-type: none"> • Patient and Family Advisory Groups
	<i>Organization</i>	<ul style="list-style-type: none"> • Patients in leadership and governance • Patients on steering committees, in boards 	<ul style="list-style-type: none"> • Patients on hiring committees • Patients on internal committees 	<ul style="list-style-type: none"> • Patients co-author materials or train new staff at orientation 	<ul style="list-style-type: none"> • Surveys • Secret shopper programs • Patient and Family Advisory Groups
	<i>Geographic region/system level</i>	<ul style="list-style-type: none"> • Creating health policy together 	<ul style="list-style-type: none"> • Patients as politicians 	<ul style="list-style-type: none"> • Patients involved in developing national care guidelines 	<ul style="list-style-type: none"> • Surveys • Election results



Parity
*Numbers, Compensation, Power balance & comfort level
Preparation & support, Training, Leadership, Vulnerability*

Figure 1. A Framework for Patient-Professional Partnership, and some examples

Factor 1: Place

At what level is the partnership taking place?

The first theme is the level of partnership is **Place**: where within the system of health the partnership is occurring or what level of the health care system the partnership hopes to improve. For example, partnership can take place in the face-to-face meeting between a patient and provider (direct care level) through the use of decision aids, on a clinical level in the form of improvement teams that include both patients and providers, in a hospital or health care organization by including patients in governance and leadership, or on regional, national or global level to shape or create policy.

Patients and professionals have developed strikingly similar models for describing a structural hierarchy of expanding concentric circles to diagram this process of contextual influence.

Place from patients' perspectives

Many patients describe an advocacy journey that begins with gaining mastery over one's personal health situation and continues by expanding to larger and larger spheres of influence in order to improve health care for others. As breast cancer survivor and advocate Musa Mayer writes:

"The path of healthcare advocacy usually begins with a devastating illness or condition, our own, or that of someone we love. Fear, grief, and helplessness are transformed through learning into action. As we become 'experienced' patients, moving past our initial coping with diagnosis, symptoms and treatments, many of us are motivated to reach out to others who are coping with our condition, to give back as we've been given to. In an effort to make a broader impact, some of us then begin a lengthy process of self-education so as to understand the medical aspects of our disease and science behind the condition and its treatments more fully. If research becomes a particular interest, we then undertake training to learn about scientific methodology and evidence-based healthcare, research design, basic statistics, and epidemiology.

What begins as difficult personal experience is eventually transformed into an avocation and a mission to be of help to others. Often, we discover in our advocacy a chance to pursue undeveloped interests and skills. But we always begin with the authenticity of our own experience."

Place from professionals' perspectives

Professionals too have developed models depicting the concept of concentric circles expanding to wider levels of context. These include Bronfenbrenner's ecological model, as well as concepts of micro, meso and macro improvement used by the Dartmouth Institute and in Jönköping, to name but a few.

The figure below shows the similarity between these models.

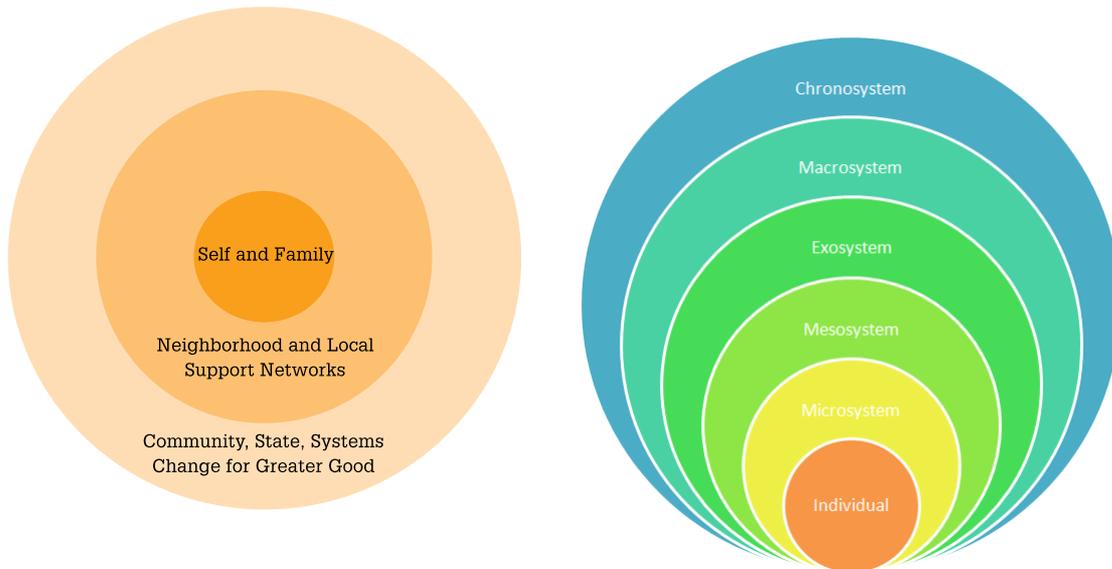


Figure 2. A patient (left) and a professional (right) model depicting the concentric circles of context. Left: *Concentric Circles of Family Leadership*.⁴ Right: *An ecological context diagram adapted from Bronfenbrenner's Ecological Model*.⁵

Implications of Place

Examining the **Place** or level at which partnership can be helpful for a number of reasons:

- Different levels may require different skills and knowledge.
- As described in Musa Mayer's quote above, some patients report that it is helpful to feel a sense of confidence around one's own health situation (micro) before participating in clinical improvement projects (meso) or broader systemic needs (macro). If this is true, supporting patients in their own health may be one way for health care organizations to support future patient advocate leaders to be able to more comfortably working at higher levels.
- Organizations pursuing a greater commitment to partnership may find it necessary and effective to create opportunities for partnership on as many levels as possible. It is not uncommon for an organization to push front-line staff to increase partnership with patients at the clinic level while restraining patients from governance and leadership positions. This can be a lost opportunity.
- It could also be worth reflecting on how the concentric circles of leadership model applies to professionals as well as patients, and how this model might serve as a "journey roadmap" for professionals as well.

Factor 2: Phase

At what point in the project is partnership beginning?

As mentioned above, patients have traditionally not been encouraged to play active roles in health and care improvement. As we develop more precise mental models and frameworks to discuss patient-professional partnership, it can be helpful to further specify what we mean when we talk about partnership.

⁴ From the National Institute for Children's Health and Healthcare Quality (NICHQ) publication, *Powerful Partnerships: A Handbook for Families and Providers Working Together To Improve Care*.

<http://www.nichq.org/documents/powerful%20partnerships.pdf>

⁵ From <http://asilearnhowtoteach.blogspot.se/2010/12/my-ecological-context.html>, on March 3, 2014.

Regardless of industry, the execution of a project or the development of a system typically includes these four phases:

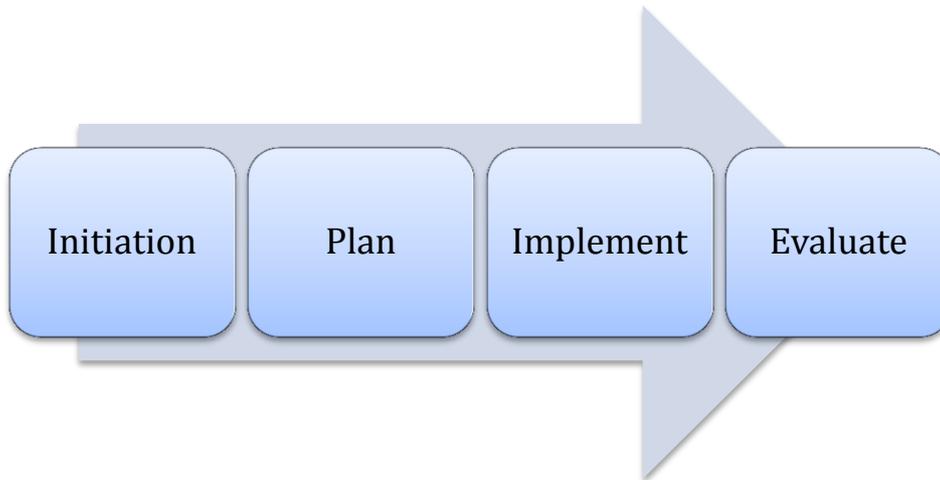


Figure 3. The phases of project execution/system development life cycle

Initiation refers to the selection of a problem to solve or a need to meet and the designation of the necessary resources. In health care, professionals have typically held this *formulation privilege*, deciding the scope of the issues as well as their prioritization. Therefore, initiatives can be perceived as patients and families to have a narrow focus or to be the solution to a low-priority problem. Projects which include patients and families in this phase are thought to be more likely to address more complex issues like multiple chronic conditions, social determinants of health, whole person health and well-being, and public/community health.

Planning involves determining what will be done, by whom and by when. Patients and families are beginning to take on planning and leadership roles in projects and development in an effort to ensure that implementation and evaluation of the initiative is conducive to patient involvement. For example, a patient leader can use their experience from previous partnership projects on a planning team to help the team address issues around training or compensation needs. It also sends a strong signal to all stakeholders that patients and families are seen as leaders by the organization.

Implementation is the actual doing of the tasks. On the micro level of one's own care, patients are now being included in co-producing their care through shared decision making, identifying their values, or tracking their own data. On the meso level patients are now writing materials or books, presenting at conferences, serving as teaching faculty, participating in project teams, conducting interviews with other patients, working as patient navigators or coordinators, and much more.

Evaluation is the reflection on how well the project itself was executed (process) and whether it met its objectives (outcomes) after the project is finished or the service has been delivered. A suggestion box in the reception area of a clinic was often the most common way for a provider to collect feedback, although systems are becoming more sophisticated. The US HCAHPS⁶ and Swedish *Patientenkät*⁷ and Lex Maria⁸ are just a few examples.

⁶ <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HospitalQualityInits/HospitalHCAHPS.html>

⁷ http://www.skl.se/vi_arbetar_med/halsaochvard/nationellpatientenkatt

⁸ <http://www.socialstyrelsen.se/lexmaria>

Implications of Phase

In the context of patient-professional partnership in healthcare improvement, being aware of the phase during which patients and professionals intentionally come together to begin collaborating can have profound effects on the outcome of the work.

It is generally understood that both patient and especially health care as a system has the most experience and is therefore most comfortable partnering with patients in the evaluation stage of a project. Conversely, the earlier the partnership takes place, the more challenging it can be.

As patients, families and patient organizations become more savvy and experienced, it will be more difficult for health care institutions to isolate patient partnership to later phases of projects. Patients have already begun signaling a sense of tokenization by health care that they are being used to further an organization's agenda without being given equal status.

Challenges to early-phase partnership include:

- Lack of existing routines to incorporate patients in governance decisions
- Fear that involving patients in early-phase decisions would raise unreasonable demands⁹
- Limited time, i.e. fast turnaround in grant applications, etc., make it difficult to partner with patient organizations, especially when patient organizations need time to recruit and prepare appropriate partnership participants.

Factor 3: Parity

How are conditions in the relationship being addressed so that all people can participate fully and successfully?

In addition to the factors described above, there are also a number of other subtle factors that I will gather under the heading Parity. Parity refers to the state or condition of being equal or congruent. In our framework, Parity refers to the removal of barriers or addition of supports that equalize power.

Parity might include such factors as:

- Parity in **numbers**. When patients and professionals are working together in a committee or working group, is there an appropriate and even balance of voices or votes? If two patients and 10 professionals are participating, it may not be possible for a patient to have their perspective heard. Another example is isolating patient representatives from each other or not replacing them when they need to take time off to address health issues.
- Parity in **compensation**. Are all members of the group being compensated fairly for their contribution? Are patients being asked to lay out funds for travel or other expenses? This may be a barrier to recruit a diverse range of people.
- Parity in **power balance** or **comfort level**. Patients have traditionally held less power than health care professionals in their patient-professional relationship, and as a result patients who are acting as advocates may need explicit encouragement and support to participate. Using meeting facilitation techniques that ensure that everyone has a chance to speak is one example. Conversely, professionals may feel uncomfortable being open and honest about some of their challenges, and their patient colleagues may need to make an extra effort at the outset to establish trust and a supportive relationship.

⁹ Survey Shows That Fewer Than A Third Of Patient-Centered Medical Home Practices Engage Patients In Quality Improvement. Esther Han, Sarah Hudson Scholle, Suzanne Morton, Christine Bechtel, and Rodger Kessler. Health Aff February 2013 32:368-375;doi:10.1377/hlthaff.2012.1183

- Parity in **preparation and training**. Successful participation in many efforts typically require a certain amount of knowledge regarding pre-existing systems or conditions. It is important that both patients and professionals have been adequately prepared and oriented from the beginning so that they feel comfortable and competent.
- Parity in **support**. Partnering in new ways can be challenging, and patients and professionals may benefit from on-going support or personal mentorship. At the very least, each individual should have a designated contact person for questions or concerns.
- Parity in **leadership**. As a means to establish equality in work groups, meeting roles including leadership are frequently rotated among all members. This demonstrates that all members are valued as leaders and are also given support to grow into this role if they feel they need it.
- Parity of **vulnerability**. Frequently, participating as a patient in partnership activities requires sharing personal experiences as a way to move the team toward understanding and action. Participating as a professional can mean sharing mistakes and shortcomings. If either group feels more vulnerable than the other, it can be difficult to establish a trusting relationship. Finding tools to support each other to be vulnerable can be helpful.

Using the Patient-Professional Partnership Framework

QRC can use the Patient-Professional Partnership Framework to measure and improve the patient perspective within their organization in several ways:

- Using the Framework, document where patients are currently present in projects and objectives.
- If patients are not present in certain Phases or Places within the framework, examine how they might be included.
- If patients are included, review the list of Parity factors to explore how patients and professionals might be better supported through training, mentorship, compensation or other resources to enable more authentic engagement. Consider including trusted patient advisors in this conversation and invite them to give open feedback.
- Consider scheduling periodic assessments of the organization as a whole using the Framework to evaluate progress and as part of strategic planning initiatives.

III. Cutting edge examples of patient-professional partnership

Below are a few examples of projects that demonstrate a greater degree of patient-professional partnership than average health care systems or organizations. Many others exists, but these have been selected for their diversity.

EX-Center: Co-governing clinics

[EX-Center](#) at Rehabcenter Sfären in Stockholm is a habilitation, rehabilitation and information clinic for children, youth and adults with congenital limb deficiencies or amputations. It is particularly innovative in that it is co-run by Bräcke Diakoni and the Swedish Thalidomide Society, a non-profit patient advocacy organization and was started in 1993.

Working from whole person perspective, the multi-disciplinary teams include an orthopedic physician, a physical and occupational therapist, a psychologist, and a care coordinator, who is herself patient. Patient peers also participate on teams as role models, in a noteworthy and unusual partnership activity. A 2013 [video](#) of the clinic focusing on partnership shares some of the challenges and opportunities of this governance arrangement.

Jönköping självdialyskliniken: Co-designing treatments

At the [self-dialysis clinic](#) at the Jönköping County Hospital Ryhov, patients can perform dialysis on themselves. The clinical model is a result of partnership between a patient, Christian Farman, and his nurse, Britt-Marie Banck. The clinic has reduced staffing by 25% compared with traditional dialysis clinics, and today 58% of patients perform their own dialysis. Of note is also the addition of a patient support peer, who is on-staff to assist other patients, as well as Learning Cafés, peer-to-peer group visits designed to educate and support patients.

ImproveCareNow network: Learning health networks with all stakeholders as teachers and learners

The [Improve Care Now](#) network out of Cincinnati Children's Hospital is a learning health care network for improving the health of children and youth with Irritable Bowel Disorder. In some ways, it resembles some forward-thinking Swedish registry systems. The network consists of 66 clinics, 535 providers serving 18,700 children, along with researchers, service designers and quality improvement specialists. Through the use of innovative platforms such as an IBD registry and the ICN Exchange, an internal knowledge-sharing platform, the ICN clinicians, researchers, patients, families and improvers can share best practices, treatment and symptom data, and support.

Despite the fact that no new pharmaceutical has been developed for the treatment of IBD, remission rates since the inception of the network have increased from approximately 50% to 75%. This is attributed to spread of best practices among the leading clinics, among other factors.

Though similar to Swedish registries, the ICN network seems to leverage patients' knowledge and expertise to teach and support not only other patients but also other team members, as well as the way in which clinics support each other in quality improvement more than is currently observed in Sweden.

CHIPRA and Cambridge Health Alliance: Patients on clinical improvement teams

The adoption of quality improvement methodology by clinical improvement teams is not entirely new within health care in the US or in Sweden. However, many sites in the US are now including (and even mandating) patients and families as active members of improvement teams. Two examples of such initiatives include the [Cambridge Health Alliance](#), a community hospital system and teaching hospital for Harvard Medical School, and the [Massachusetts CHIPRA program](#). Both initiatives include 12-13 primary care clinics each. As full team members, patients and family members participate actively in learning collaboratives, identify opportunities for improvement, design and run PDSA cycles, and facilitate spread. The idea behind this adaptation of traditional improvement teams is that by having a patient embedded in the work team, the entire team will be more likely to produce person-centered improvement initiatives. In addition, there will be a continuous feedback loop from patients and families throughout the improvement process.

Massachusetts patient-advisory councils: Mandated partnership

Although the concept of patient-family advisory councils is not new to hospitals, in 2010 the state of Massachusetts in the US was the first to [mandate that all hospitals have a PFAC](#), as well as a plan for supporting it, or risk losing their funding. This example shows how patient-professional partnership activities are becoming more system-supported rather than relying on individual champions to support the cause.

Experio Lab: New competencies to improve health care systems

[Experio Lab](#) is a Swedish national center for health care service innovation. Part of the County of Värmland, the initiative involves patients, families and clinical professionals in order to create and improve health care services. By using service design methods and embedding designers in care teams, the aim is to integrate patient-centeredness and partnership more fully in care delivery and design.

Patient-Centered Outcomes Research Institute: Patients as partners in research

In an effort to ensure that patients become partners not only in health care but also in research, the US government launched [PCORI](#), a multi-billion dollar initiative in which patients and families support the development of patient-centered research questions, studies and dissemination. Patients and families are part of the committees reviewing grant applications and awarding funds. Grants are awarded according not only to scientific promise but also to the research teams' ability to partner and include patients and families.

Society for Participatory Medicine: Multi-stakeholder associations

The [Society for Participatory Medicine](#) is a US-based non-profit organization which aims to promote the idea of participatory medicine, which they define as "a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners." Members of the organization are both patients and professionals, and the organization takes on a number of activities that encourage partnership between patients, their families and caregivers. Through their [Journal of Participatory Medicine](#) as well as their blog [e-patients.net](#), they also provide a forum where patients and professionals can share ideas and perspectives on issues, challenges and strategies for effective partnership. The organization also provides a forum for patients who are engaged in health care improvement work but are not affiliated with a disease-based advocacy organization, such as Dave deBronkart, also known as e-patient Dave.

The National Institute for Health and Care Excellence (NICE) and the Guidelines International Network (G-I-N): Patients as partners in developing care guidelines

The UK's [National Institute for Health and Care Excellence](#) is responsible for developing the nation's guidelines for evidence-based guidelines for health care, public health, and social services interventions. Patients and families serve on the working groups to develop these guidelines. As a result, the guidelines are thought to be more relevant to the needs of patients and their families. Similarly, the [Guidelines International Network](#), G-I-N, is a global network of 96 organizations and 117 individual members representing 69 countries from all continents. The network supports the development of clinical health guidelines.

IV. Trends and shifts

From the real-world examples above and others like them, we can deduce a number of trends that are occurring in patient-professional partnership, and the system and cultural shifts that we believe will take place in order for partnership to spread and flourish.

From surveys to co-design. Patients will be involved earlier in projects and at all (micro, meso, and macro) levels, including in the design of services, systems and policy. The realization that the inclusion of patients and families ensures a higher likelihood of success will spur a desire from professionals for more tools and support so that they can include patients earlier and more often. Patients and patient advocacy organizations will also reach out to professionals to work more collaboratively as a means to develop solutions that are more effective and holistic.

From engagement (*inflytande*) to partnership. Rather than partnership being seen as a professional-initiated activity in which patients are invited to join when it suits health care, partnership will become a more reciprocal activity, with a particular focus being put on finding common interests in the project early on. Projects which continue to include patients as an afterthought will be viewed more often as tokenistic and may have a difficult time seeing real value from their efforts.

From patient empowerment to collective empowerment. While it will be important for patients and patient advocates to strengthen their own identity, rights and power, eventually we will move to a paradigm in which the goal is not simply strong patients but

a strong health care system. The desired output of partnership will not simply be the creation of more person-centeredness, but of a system that benefits all stakeholders, including professionals and society as a whole.

From passionate champions to supportive systems. Right now, patient-professional partnership relies heavily on the presence of a passionate champion. In the future, systems for training, measuring, and compensation will support widespread partnership so that it is the rule, not merely the exception. Both sticks and carrots, in the form of requirements and incentives, will be developed and implemented.

From parts to wholeness, from health care to health. Network-based thinking will create a need to bridge specialty silos and expand the focus of health care from fixing body parts to prevention, population health, integration of medicine, behavioral health and social services, and the rise of technology- and community-enabled self-care. Even, the current organization of patients according to disease-focused advocacy organizations will also be inadequate. Already the question of which patients get a seat at the table in areas like primary care is becoming problematic. Involvement of patients in larger health contexts will mean that sometimes, a patient is not representing only people with their disease, but all users. And sometimes, they are not representing anyone, merely being themselves, just the way providers do when they participate on projects.

From “to” or “for” to “with.” Increasingly, there will be a realization that patient-centered care and patient-professional partnership are not one and the same. Professionals seeking to create person-centered care without including patients will recognize the impossibility of the task. Patients, too, will realize that what they seek is not for professionals to care for them but to care with them. Both professionals and patients will be acknowledged as teachers and students. A shift away from paternalism and victimhood will give way to a collegial relationship. To support this new professionalism, new collaborative platforms and professional associations in which we can all learn together will be developed.

V. Needs for improving partnership

There are a number of barriers cited frequently by both professionals¹⁰ and patients when asked why they are not currently working more closely together or including each other in their work. “We would have liked to include them, but we didn’t have the time (or money)” is one of the most frequent ones given, though there are more deeper rooted issues of trust or perceived value that can often prevent a need for collaboration, i.e. “We already know what they think.” Connecting these barriers with the shifts listed above, below follows a select list of requirements if we are to increase partnership.

New competencies and knowledge. In order for partnership to flourish, patients and professionals will need new language, models, concepts, frameworks and tools. Patients will need a greater understanding of systems thinking, the health care system, improvement/design concepts, and get better at translating their own experiences into improvement and policy. Professionals will need to widen their mindset to include patients’ priorities and working styles, which may differ greatly from the way they are used to working. Creating and spreading this knowledge will require research, evaluation, training, and mentorship.

Time. Building trust, capacity and relationships take time. Diving into a project without giving adequate time for patients and professionals to understand each others’ motives and recognize each others’ strengths will lead to frustration and tokenism. Projects and

¹⁰ Survey Shows That Fewer Than A Third Of Patient-Centered Medical Home Practices Engage Patients In Quality Improvement. Esther Han, Sarah Hudson Scholle, Suzanne Morton, Christine Bechtel, and Rodger Kessler. Health Aff February 2013 32:368-375;doi:10.1377/hlthaff.2012.1183

grant applications with tight turnaround times are frequently cited by health care professionals as a reason for not including patients. Building in time for trust- and team-building activities is challenging but essential.

Money. Compensation for new stakeholders, staff to support partnership, and training all require funding. Current financial incentives and pay-for-service payment models do not support the inclusion of patients. Typically, professionals often realize after a budget has already been set that they will need funding to include patients.

Supportive systems. Legal requirements and financial incentives can go a long way in creating consistent, supported partnership and to help avoid workarounds led by champions. Both carrot and stick methods, i.e. mandates, reimbursement models, awards and financial incentives will need to be developed within organizations and within society as a whole. Leadership can also require that the teams they manage include multiple stakeholder perspectives or that they work using techniques and methodologies which increase partnership, such as a service design approach.

Culture change. A significant challenge to increasing partnership is the culture of health care itself. The medical model, the pervasive cultural paradigm dominating health care for the past century, places the expertise of professionals above the self-efficacy of patients. Even in committed clinics or organizations where patient-professional partnership is the ideal relationship model, this systemic resistance can reveal quickly itself. In Sweden, the paternalistic model of physician-patient relationship (*omhändertagandekultur*) dominates health care culture, providing an additional challenge to those working to improve in partnership.¹¹

VI. Conclusion

Technology guru and author William Gibson once said, "The future is already here — it's just not very evenly distributed." Surveying the landscape of current health care efforts involving patient-professional partnership, it is clearly a rapidly evolving arena for innovation and improvement. Whether from a desire to increase value or citizen democracy, it is also clear that the Pandora's box of patient-professional partnership has been opened permanently. Organizations that actively seek out ways to partner with patients need and want tools and resources to facilitate this shift.

Even if it has not yet permeated every aspect of health care and health culture, innovative projects led by forward-thinking people and organizations are shining a path toward a future that seems to include less paternalism and more collaboration.

We believe that organizations which invest the time and energy to increase partnership within their organizations will have a competitive advantage.

Select web-based resources for patient-professional partnership

G-I-N PUBLIC's [Toolkit on Patient and Public Involvement in Guidelines](#)

National Institute for Children's Health and Healthcare Quality's [annotated bibliography of resources pertaining to patient-professional partnership](#), part of their toolkit on creating practice-based patient- and family-advisory councils in pediatric primary care practices.

¹¹ Vårdanalys Rapport 2012:7, p 88

RCC and SKL Guide: [Mer patientinflytande – bättre cancervård](#)

Robert Wood Johnson Foundation's [Engaging Patient in Improving Ambulatory Care: A Compendium of Tools](#)

The NHS [Patient and Public Engagement Toolkit for World Class Commissioning](#)

The Agency for Healthcare Research and Quality (AHRQ) [Guide to Patient and Family Engagement: An Environmental Scan](#)

A toolkit for practices seeking to include patients and families on quality improvement teams: [The Cambridge Health Alliance Practice Improvement Team \(PIT\) Development Toolkit](#)

Delad kunskap ger bättre hälsa

QRC Stockholm är ett nationellt och regionalt kvalitetsregistercentrum. Vår vision är att QRC Stockholm ska bidra till en bättre hälso- och sjukvård genom att vårdens personal, patienter, beslutsfattare, forskare och näringsliv regelbundet använder kvalitetsregister. Vi stödjer registerhållare att utveckla kvalitetsregister för att följa upp och förbättra vården över tid. Våra profilmråden

- Patienters medverkan i den egna vården, i uppföljningen av vården genom register samt i forskning.
- Registeranvändning i klinisk verksamhet – utveckling av användbara analysverktyg och beslutsstödsystem i samverkan mellan register, vårdpersonal, patienter, forskare och företag.
- Integration av register, journalsystem och beslutsstöd för effektivare datainsamling, ökad användning av medicinsk evidens i klinisk praxis och bättre uppföljning.
- Forskarstöd och samordning av register för forskning på ett innovativt och utvecklande sätt till nytta för alla patienter.

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