PATIENT AND FAMILY ENGAGEMENT

PARTNERING WITH PATIENTS, FAMILIES, AND COMMUNITIES FOR HEALTH: A GLOBAL IMPERATIVE

Report of the Patient and Family Engagement Working Group 2013

Susan Edgman-Levitan and Carrie Brady with Peter Howitt

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FOREWORD

The fundamental question facing each nation is the same – how can we best promote the health of our people? Health ministers attempting to answer this question are confronted by a dizzying array of possibilities, competing priorities, limited resources, and a morass of interdependent factors that affect and are affected by health. Ministers make the best decisions they can with the information available, often seeking expert opinions and "best practices" that can be adapted and implemented locally. The most important "experts," however – ordinary people managing their own health – are typically left out of the discussion.

The solutions to the health challenges of today and tomorrow won't come from doing business as usual; they will come from building effective partnerships and harnessing the untapped global power of ordinary people who care about improving their health. That is what the UN and World Health Organization have recognized in their development of the post-2015 agenda: they have sought public advice, through a series of consultations and an online global survey. More than one million people, representing 194 countries, participated in the survey, and in their responses, they confirmed the primacy of two goals: "a good education" and "better healthcare."[1] These goals are world priorities, for governments and for their people.

Not surprisingly, the two goals are linked. Better education contributes substantially to improved health. The Global Thematic Consultation on Health has recommended that the post-2015 agenda "take a holistic, life-course approach to people's health with an emphasis on health promotion and disease prevention."[2] Health literacy, "the capacity of individuals to obtain, interpret, and understand basic health information and services necessary for appropriate health decision-making,"[3] will be a key foundation for success.

Education of the public and health professionals is one of six areas in the Global Health Partnership Framework described in this report; the others are research, community health, direct care, organizational design and governance, and public policy. As shown by the various examples of successful programs cited in this report, there are powerful benefits to be derived from partnering with patients, families, communities, and healthcare workers at all levels. Partnership is key to the "health diplomacy... process of engaging, motivating and communicating amongst multiple parties to develop policies and programs that advance sustainable health outcomes."[4] Whatever health challenges face your country, effective engagement will prove to be an important part of the solution.

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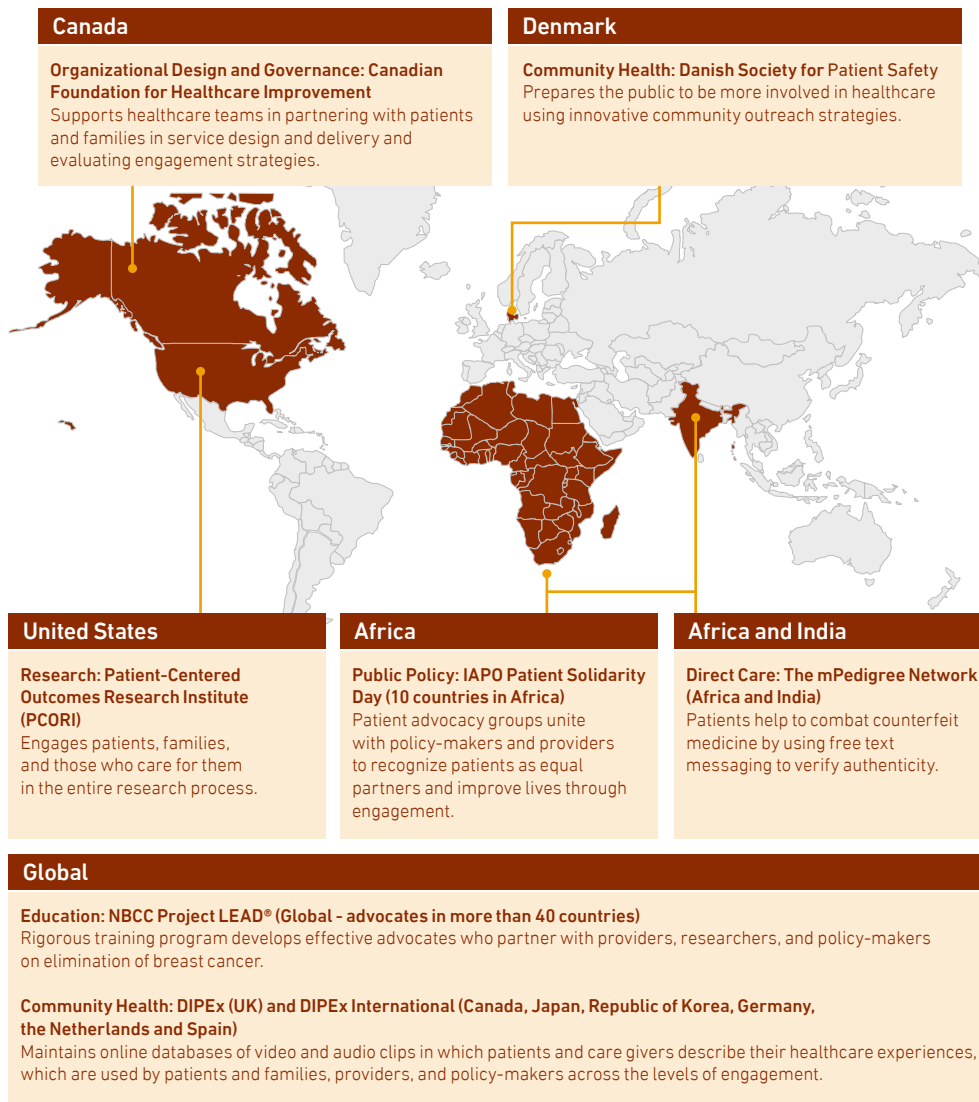Massachusetts General Hospital

EXECUTIVE SUMMARY

Involving people in healthcare (what this report calls "engagement") is very powerful, but how can it be used to achieve change? This report introduces a new Global Health Partnership Framework to clarify opportunities for innovation.
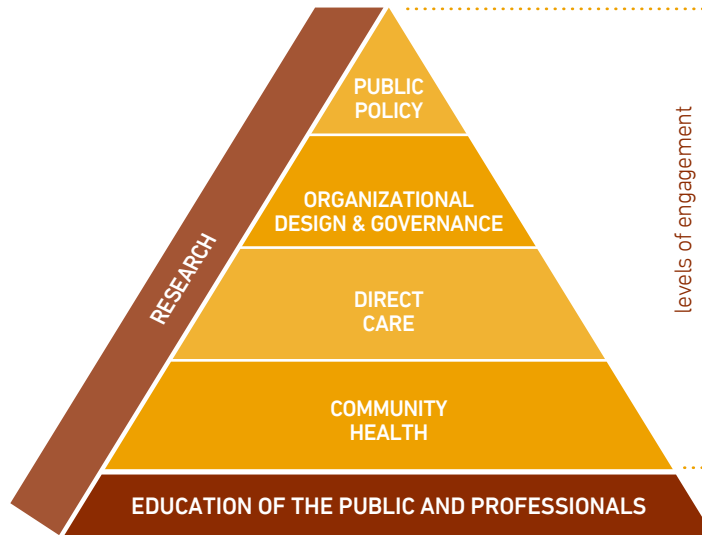
The next two sections of this report explain that engagement is an essential tool for health ministers to improve global health, as it promotes effective stewardship and utilization of limited resources. As it depends on flexible partnerships with local people, it is a scalable solution applicable to any country and any health challenge. It reflects and incorporates multi-faceted healthcare needs, and helps to avoid wasted resources and effort. Engagement in healthcare could be the "blockbuster [solution] of the century."[5]

Despite its potential, however, there are many barriers to engagement. Demonstrating that these barriers can be overcome, and that the benefits far outweigh the challenges, the *Effective Engagement* section highlights successful and diverse engagement programs from around the world, including those in the map.

Canada

Organizational Design and Governance: Canadian Foundation for Healthcare Improvement
Supports healthcare teams in partnering with patients and families in service design and delivery and evaluating engagement strategies.

Denmark

Community Health: Danish Society for Patient Safety
Prepares the public to be more involved in healthcare using innovative community outreach strategies.

United States

Research: Patient-Centered Outcomes Research Institute (PCORI)
Engages patients, families, and those who care for them in the entire research process.

Africa

Public Policy: IAPO Patient Solidarity Day (10 countries in Africa)
Patient advocacy groups unite with policy-makers and providers to recognize patients as equal partners and improve lives through engagement.

Africa and India

Direct Care: The mPedigree Network (Africa and India)
Patients help to combat counterfeit medicine by using free text messaging to verify authenticity.

Global

Education: NBCC Project LEAD® (Global - advocates in more than 40 countries)
Rigorous training program develops effective advocates who partner with providers, researchers, and policy-makers on elimination of breast cancer.

Community Health: DIPEx (UK) and DIPEx International (Canada, Japan, Republic of Korea, Germany, the Netherlands and Spain)
Maintains online databases of video and audio clips in which patients and care givers describe their healthcare experiences, which are used by patients and families, providers, and policy-makers across the levels of engagement.

The *Opportunities for Action* section makes the concept of engagement more concrete by identifying various opportunities for action that ministers can take to foster engagement at each level. The highest-impact recommendations in each category are highlighted below.

Education	*Patients and Families:* • Develop and implement programs to improve the health literacy of the population, including enhancing primary and secondary education curricula to incorporate content related to physical and mental wellbeing, health literacy, statistical and risk literacy, self-care, and skills to enhance partnering with healthcare professionals. *Healthcare Professionals:* • Create patient and family faculty programs to educate healthcare professionals about the experience of illness and the patient and family perspective on what constitutes high-quality care.
Community health *Continued overleaf*	• Offer evidence-based sources of health information and decision support tools to people through effective dissemination strategies such as electronic portals, cell phones, and alternative low-tech tools (paper-based, for instance). • Partner with community organizations to improve health literacy, raise awareness of common health threats, and to enhance access to necessary health services.

Recommendations continued	
Direct care	• Set public expectations that every healthcare professional will routinely invite them to participate in informed decision-making, and will partner with patients and families to support their goals, as they define them. • Promote self-management of medical conditions, through the use of effective materials and through coaching, support, and connections to community resources.
Organizational design and governance	• Engage patients and family members in developing and reviewing all communication and educational materials designed for patients and families to ensure that they are relevant and clear. • Mandate that all healthcare organizations will engage patients and families as partners in quality improvement, care design and redesign, and policy-setting through development of patient and family advisors and programs that have sufficient resources and training to be effective.
Public policy	• Directly engage the public in policy-making, using methods such as in-person consultation and placement on decision-making boards, and through the use of emerging methods such as social media and crowdsourcing. • Examine and align incentives for the public, healthcare organizations and governmental agencies to promote engagement of the public.
Research	• Require research funding entities to set the expectation that patients and families will be involved in all aspects of research activities they fund, including establishing study aims, design and methodology, and outcome measures. • Continue to build the evidence base for effective engagement strategies across different cultures by integrating evaluation plans into the design of any engagement initiative.

Of these priority recommendations, perhaps the most powerful is the first – to improve health literacy. Improving health literacy provides a solid foundation on which to build other engagement strategies; targeting women in particular is a powerful way to address family and community health. One recent study suggested that half of the global reduction in child mortality over nearly four decades is attributable to the increased educational attainment of women of reproductive age.[6]

The aim of this report is to stimulate both dialogue and action. The final section accordingly lists some immediate "next steps" – three activities for improving engagement. They are, in our view, relevant to every country, and provide important opportunities for continued global collaboration. They are:

1. **Sign the Declaration on Engagement for Global Health** to demonstrate support for engagement at all levels of the Global Health Partnership Framework and to commit to taking action to address one of the priority recommendations.

2. **Sponsor a Health Engagement Day** in conjunction with community partners, to begin engaging patients, families, and communities in health.

3. **Participate in international Change Day** on March 3, 2014, by inviting patients, families, communities, and healthcare workers to make personal commitments to engagement.

REDEFINING GLOBAL PATIENT AND FAMILY ENGAGEMENT

To use engagement effectively to promote global health, we must first develop a shared understanding of what engagement means. The phrase 'patient and family engagement' and similar terms such as 'patient and family activation', 'empowerment', and 'participation' tend to suggest a narrow focus on ways of changing patient and family behavior, without recognizing that healthcare professionals must change their behavior as well. We define family as the entire circle of people that the patient chooses to involve in his or her healthcare, not just those individuals connected to the patient by biology or law. Healthcare professionals must learn to be better partners, not only with patients, families, and communities, but also within their own organizations, between leaders, clinicians and staff. Effective engagement for global health is not about achieving patient "compliance" with professional recommendations; it is about building skills and tools to promote dialogue and relationships between patients, families, healthcare professionals, and the community. We propose to change the clinical paradigm from "What is the matter?" to "What matters to you?"[7]

Engagement is often described as an essential foundation of patient and family-centered care, but the World Health Organization (WHO) has taken the concept further by embedding engagement in "people-centered care," which it defines as:

> "Care that is focused and organized around the health needs and expectations of people and communities rather than on diseases. People-centred care extends the concept of patient-centred care to individuals, families, communities and society. Whereas patient-centred care is commonly understood as focusing on the individual seeking care – the patient – people-centred care encompasses these clinical encounters and also includes attention to the health of people in their communities and their crucial role in shaping health policy and health services".[8]

The WHO's Western Pacific Region has further defined people-centered care as including engagement of healthcare professionals, noting that "health practitioners are people, and healthcare organizations and systems are made up of people. Their needs should also be considered, and they must be empowered to change the system for the better."[9] Indeed, the desire to help patients and families achieve their healthcare goals and improved quality of life is what motivates most people to become health professionals. By improving their skills to support patient and family engagement, healthcare professionals improve their work satisfaction and their own quality of life as well.[10]

Engagement is multi-dimensional. It can take the form of a very personal event, such as a shared decision between an individual patient and healthcare professional; or it can be a systematic public event, such as a health literacy campaign. It can be targeted at improving provider performance, as when patient and family advisors and healthcare professionals redesign healthcare services together; or it can be targeted at informing patient behavior, as through self-management programs for chronic disease. It can begin with simple information-sharing, move on to dialogue, and evolve into partnership. Whatever form it takes, engagement changes the focus, from taking action to improve health and healthcare for the people, to taking action with the people – a simple yet radical notion.

The Patient and Family Engagement Forum has developed a framework of engagement to help countries assess their current programs and think strategically about future engagement opportunities – about using engagement to promote people-centered care and global health. The Global Health Partnership Framework draws heavily upon the work of two different teams of researchers,[11] but it adapts their models to reflect the experience of Forum members and the analysis of the case studies. The framework incorporates six key opportunities for building relationships between individuals, families, communities, healthcare professionals, and policy-makers. They are: education, research, community health, direct care, organizational design and governance, and public policy.

The first two categories, education and research, are foundational, and infuse each of the other four levels. Education will drive changes in behavior across the levels of engagement. It is necessary not only for individuals and families, but also for healthcare professionals, who need to learn new skills for partnership communication. As for research, it often is a key driver of healthcare policy, professional practice and patient outcomes. When research is designed with the help of patients, families, communities, and frontline clinicians, what emerges is a set of different questions and priorities, and hence different results.

The four levels of engagement reflect different types of interactions:

- At the **community health** level, individuals are not under the care of a healthcare provider, but are making decisions that affect their health. Key decisions at this level include whether and when to seek professional care, and how to maintain health and wellbeing.

- At the **direct care** level, individuals have become "patients" interacting with the healthcare system. When they are no longer under the direct care of a healthcare worker for a condition, they return to the community health level.

- At the **organizational design and governance** level, healthcare professionals partner with current and former patients and families to improve their services.

- At the **public policy** level, individuals and communities work with health agencies and other organizations to develop policies that support health and healthcare.

GLOBAL HEALTH PARTNERSHIP FRAMEWORK

	LEVELS OF ENGAGEMENT		
EDUCATION	**Community health**	Engagement of the public before they access the healthcare system (for example, "developing household capacities to stay healthy, make healthy decisions and respond to emergencies,"[12] and making informed decisions about when to seek healthcare from professionals) or after access, when they are no longer under the direct care of a healthcare worker.	**RESEARCH**
	Direct care	Relationship between healthcare professionals, patients and families in the context of individual care for a health condition (for example, shared decision-making, self-management of chronic conditions).	
	Organizational design and governance	The involvement of patients and families in influencing the way that the organization provides care (for example, patient and family advisory councils, patient and family partners for process improvement).	
	Public policy	The involvement of patients and families in influencing public agencies' activities related to health or healthcare (for example, patient and family involvement in program development, setting funding priorities).	

Engagement is not a "one-size-fits-all" strategy. The ability and willingness to engage depend on a variety of factors that change over time – notably, the policies, practices and communication skills of healthcare professionals or organizations, and the characteristics of individual patients and families, such as burden of illness, social support, and socioeconomic status. Engagement is also heavily dependent on the cultural context of the country or community, including social norms, regulations, beliefs, and social determinants of health. As defined by the WHO, "The social determinants of health are the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels. The social determinants of health are mostly responsible for health inequities – the unfair and avoidable differences in health status seen within and between countries."[13] Successful engagement programs focus on how to be most effective within this broader context.

One of the great strengths of engagement is its flexibility, but that flexibility also hinders its adoption. The Global Health Partnership Framework described in this report is intended to guide decision-makers in using engagement to improve health. Our case studies demonstrate what can be achieved through greater engagement. Our hope is that this report will provoke more global dialogue about what engagement means in different cultures and contexts, and will contribute to a more robust evidence base of successful engagement strategies.

THE ENGAGEMENT IMPERATIVE

Now is the time to focus on engagement. As the world comes together to develop an agenda post-2015, people are making their voices heard, and are stepping forward to share their priorities and their ideas for the future. Health ministers continue to face daunting challenges, but they don't have to do so in isolation. Patients, families, and communities are eager to partner with healthcare professionals and policy-makers in meaningful ways, and have already begun organizing on their own to improve health, often using social media. Patient, family, and community involvement will undoubtedly improve the effectiveness of existing programs, but it will do more: it will also identify new solutions, and avoid wasting resources on well-intentioned but poorly designed initiatives that are destined to fail.

BENEFITS OF ENGAGEMENT

Although engagement is sometimes viewed as an end in itself, this report treats engagement as a means to an end – a powerful tool for improving global health. The tool can be applied to address cross-cutting challenges such as improving quality, reducing errors, and managing healthcare costs; and it can also be applied to address condition-specific health challenges, including other key topics of the 2013 WISH Summit. Consider mental health challenges, for example: successful management requires active partnerships with patients, families, communities and professionals. Consider end-of-life care: it can only be improved by advance planning, through which patients, families, and professionals gain a shared understanding of the patients' priorities and preferences for care. Consider antimicrobial resistance: it can be addressed by engaging patients and families in reducing the demand for unnecessary antibiotics and in completing the full course of prescribed antibiotics. Consider accountable care: an October 2013 report from The Kings Fund describes in detail the "house of care" for people with long-term conditions. Like the Global Health Partnership Framework, the model of the house of care reflects partnership at multiple levels with "engaged, informed patients" working with "healthcare professionals committed to partnership" in "personalized care planning," and it provides numerous case study examples.[14] Obesity too can be addressed in part by engaging citizens in making better nutrition and exercise choices. For obesity, though, as with any global health challenge, engaging patients, families, and communities is only part of the solution. There are a multitude of factors affecting patient, family, and community health; and public and private organizations also have key roles to play in promoting optimum health.

Researchers have investigated the effects of patient and family engagement, and have found positive outcomes such as improved quality and safety, lower costs, a better patient and family experience, and higher healthcare-worker satisfaction. Much of the analysis has been country-specific, but there are some global comparisons. For example, an 11-country survey conducted in 2011 found that patients engaging in their own care report "higher-quality care, fewer errors, and more positive views of the health system."[15]

Benefits of Patient Engagement – 2011 Survey Data from 11 Countries

The 11 Countries were Australia, Canada, France, Germany, New Zealand, Netherlands, Norway, Sweden, Switzerland, United Kingdom and United States

	Quality of care in last year excellent or very good	Experienced medical errors in last two years	Believe that health system needs to be completely rebuilt
Engaged	69	14	9
Non-Engaged	42	24	15
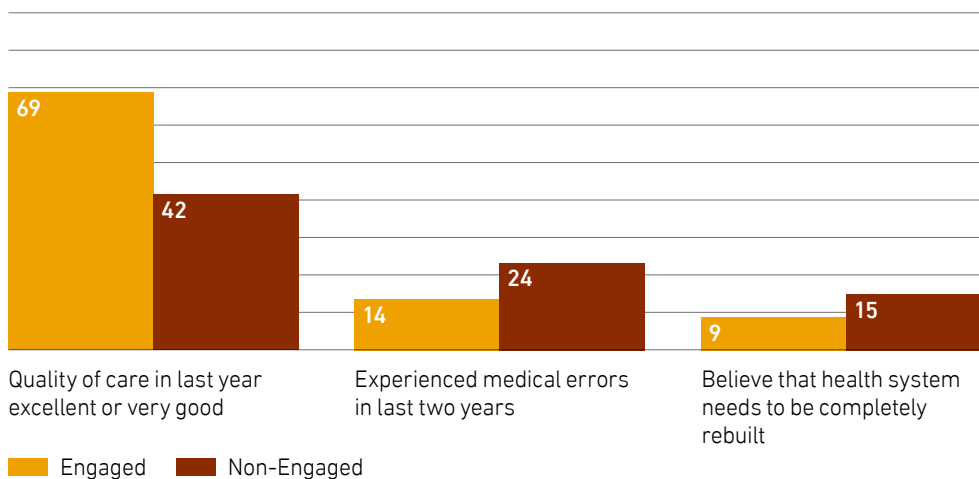
A systematic review of the evidence on four types of engagement strategies – health literacy, shared clinical decision-making, self-care and self-management, and patient safety strategies – found that all four strategies improved patients' knowledge and experiences, reduced healthcare utilization and costs, and improved health status and behavior.[16] The detailed evidence is compiled and synthesized on the Picker Institute Europe's website *Invest In Engagement,*[17] designed to help leaders evaluate the effectiveness of engagement. Another recent literature review on patient experience studies, including aspects of engagement, concluded that "patient experience is positively associated with self-rated and objectively measured health outcomes; adherence to recommended medication and treatments, preventative care such as use of screening services and immunisations, healthcare resource use such as hospitalisation and primary-care visits, technical quality-of-care delivery, and adverse events."[18] Reports by national governments and international organizations provide a global scan of the literature,[19] and research publications regularly feature emerging evidence in this field.[20] Specific engagement techniques, such as shared decision-making, have also been rigorously evaluated.[21] The uptake of engagement techniques is also being studied, for example in a Gordon and Betty Moore Foundation/Health Research Educational Trust Patient and Family Engagement Survey of hospitals.[22]

The benefits of engagement are confirmed not only by the published evidence but also by a review of successful health initiatives, many of which incorporate engagement as a critical success factor. Several of the case studies highlighted in the 2012 Global Health Policy Summit Working Group reports, for instance, and in the other seven 2013 WISH Forum reports, are rooted in effective engagement, even though they were not being evaluated as engagement initiatives. These case studies are indexed in an online Appendix for reference. A few engagement programs related to mental health are described in the WISH Mental Health Forum Report *Transforming Lives, Enhancing Communities: Innovations in Mental Health*, and several additional initiatives are included in an online compendium available at www.mhinnovation.net/innovation at each level.

BARRIERS TO ENGAGEMENT

Despite all the evidence showing the value of engagement, and despite the growing recognition of engagement as an important foundation of well-designed healthcare systems, there are formidable challenges to implementation – the result of professional norms and local cultural norms, disjointed healthcare systems, personal barriers, and misguided efforts. A brief summary of these barriers is presented here, and the recommendations for overcoming them are presented in the *Opportunities for Action* section.

Professional barriers include the following: inadequate professional training in the kind of teamwork and communication skills necessary for establishing partnerships, time pressures, difficulties in integrating enhanced communication and self-management support into clinical encounters, and misaligned incentives. In addition, health professionals often simply fail to recognize the benefits of understanding a person's experience of illness. As the WHO noted in a report on implementing person-centered care in low-and middle-income countries, "a common thread among country experiences was the resistance of health workers. They needed to be convinced through their own experience that the systematic participation of patients and communities was useful and ultimately beneficial to quality of care."[23]

All too often, the systems that health professionals work in are just not designed to foster engagement, and in some cases they are even deliberately designed to discourage it. Many systems are characterized by fragmentation of services, restrictive policies and procedures that hinder patient and family involvement, a lack of access to personal health information, and absence of leadership support for engagement. As a result, even health professionals who welcome the opportunity find themselves unable to engage patients, families, and communities effectively.

Engagement is a mutual relationship, but it is often described as a one-sided intervention to change patient behavior. This misconception contributes to fierce debates over the role of patients, families, and communities, and whether they are even interested in being engaged, especially in direct-care examples such as shared decision-making. Certainly there are many factors that reduce patients' ability to engage – notably, the patients' degree of illness, health literacy, social support, expectations, fear of retribution for "speaking up," and prior experiences. And of course, patients also vary greatly in their desire for engagement with healthcare

professionals, ranging from full partnership to complete deference; moreover, their preferences can change over time, depending on the burden of illness and the complexity of the condition. Patients should always have the opportunity to be engaged to the degree they choose.

Well-designed programs will build the desire and skills simultaneously for patients and families, and health professionals and staff.[24] Programs that fail to do so will tend to erode enthusiasm for the concept of engagement. For example, patients may initially be encouraged to ask health professionals and questions, but if they receive negative feedback, they are unlikely to repeat the behavior. Or consider educational materials that are developed for but not *with* patients: such materials may provide conflicting messages, or fail to address patient and family concerns, or may be written in language that is not clear and so will be dismissed as useless or confusing rather than helpful. Efforts at partnering must be sincere and reciprocal. If patients and families are invited to partner but aren't then treated with respect or given any meaningful opportunities to contribute, they will lose confidence in the organization and the process, and they will be less likely to engage in partnering in the future. As one patient on a hospital advisory council remarked, "We want to do more than just have lunch!"

EFFECTIVE ENGAGEMENT AROUND THE GLOBE

The programs discussed in this report have succeeded in overcoming the barriers to engagement and have achieved many of the benefits that engagement can confer. For the purposes of this report, each program has been categorized as an exemplar of a particular level of engagement, but many of the programs are applicable to multiple levels of the Global Health Partnership Framework. Many of the programs make innovative use of technology in order to foster engagement. Several programs have already been replicated in multiple nations; others remain localized to a single country, but illustrate methods of engagement that could be adapted and applied elsewhere. Note, however, that not all of the programs would work worldwide without adaptation, as effective engagement always requires a keen understanding of the local context.

EDUCATION

Patient and Family Education: National Breast Cancer Coalition (NBCC) Project LEAD®
The NBCC Project LEAD® program trains individuals to be knowledgeable and effective advocates in NBCC's mission to eradicate breast cancer. NBCC offers in-person Project LEAD® workshops at a variety of levels, from a one-day introductory course open to all to a one-week intensive training course with a rigorous application process, and follow-up courses with more detail on quality care and clinical trials. The courses focus on developing participants' knowledge of breast cancer science and public policy, and helping them to understand the evidence, to frame questions, and to think critically about health information. All Project LEAD® graduates are

supported with continuing education and collaboration, and are expected to actively partner with researchers and policy-makers and to educate the public and providers. More than 2000 advocates have participated in these courses, from more than 40 countries. Project LEAD® graduates participate on national and local research and policy committees, participate on institutional review boards, work with researchers to design clinical trials, help with education and outreach, conduct peer reviews of scientific grant proposals, and help interpret science and medical news in the media for their communities. NBCC offers periodic International Project LEAD® training focused on global clinical trials. NBCC also has recently launched an online center for NBCC advocacy training, to make some of its materials available globally on demand.

More information about the program is available at:
www.breastcancerdeadline2020.org/get-involved/training/project-lead/

Patient and Family Education: WHO Patients for Patient Safety (PFPS) Program
The WHO PFPS program works to bring the patient voice to healthcare policy and services, by engaging and empowering patients, families, communities and healthcare providers. The program is predicated on the belief that the "collective wisdom, determination and passion of the global patient population is a rich resource in the global endeavor to improve the safety of healthcare practices."[25] The collective passion of participants in the first PFPS workshop, held in London in 2005, led to the development of the PFPS global network and the "London Declaration," which enunciates the common vision, the guiding principles, and a commitment for positive engagement. The PFPS workshops have been used as a mechanism for training and orientating new advocates.

PFPS advocates are also known as "patients for patient safety champions." The majority are patients and families affected by healthcare harm. There are more than 300 PFPS advocates in 53 countries, advocating for improved quality and safer healthcare. PFPS "champions" integrate the expertise of patients and families into the work of the WHO Patient Safety program, and also partner with other organizations committed to improving safety internationally, nationally and locally. Their work spans all the engagement levels, and ranges from telling stories to raise awareness and catalyze changes, to facilitating implementation of WHO policy, to contributing to policy development, education and research.

For more information, see: www.who.int/patientsafety/patients_for_patient/en/

Health Professional Education: Ovarian Cancer National Alliance Program, Survivors Teaching Students: Saving Women's Lives®
The Ovarian Cancer National Alliance promotes earlier detection of ovarian cancer by bringing survivors into the classroom to teach health professionals. The goal of Survivors Teaching Students® is to enable future physicians, nurse practitioners, nurses and physician assistants to diagnose the disease when it is in its earlier, most treatable stages. Through this program, ovarian cancer survivors present their unique stories along with facts about the disease. Students are able to interact with and learn from actual patients. The program has been proven to increase health professionals' understanding of ovarian cancer symptoms and risk factors. It is currently offered free of charge in more than 80 medical schools, 50 nursing schools,

and 13 nurse practitioner and allied health professional programs in 29 US states, as well as in Canada and the UK. In 2012, more than 9000 health professional students were educated in this program.

For more information, see: www.ovariancancer.org/about-us/survivors-teaching-students

COMMUNITY HEALTH

Danish Society for Patient Safety
The Danish Society for Patient Safety, in partnership with TrygFonden, has created a variety of initiatives aimed at engaging patients and their families. The Patient Handbook, for example, is a written guide to hospital care that is designed to facilitate patient and family involvement. An estimated 10 percent of all households in Denmark have a copy of the handbook. The Society has also transformed the handbook into question prompts for patients to ask their providers (Just Ask) online, on cell phones and in a paper format. The site allows patients to choose specific questions, add their own, and make suggestions for others to use, and then print out the list of their questions. A study shows that 86 percent of the citizens that have received and used Just Ask in their contact with healthcare providers had an improved dialogue and asked more questions.

The Danish Society for Patient Safety uses innovative community outreach strategies to disseminate information and initiate conversations about how to be more effective partners in their healthcare. Distribution channels include healthcare providers, patient organizations, hairdressers, media, unions, and businesses. The Society has distributed 40,000 relationship-title T-shirts (for example, "better half", brother, mother) at train stations, along with information about the role that family and friends can play in the healthcare of a loved one. For its Just Ask campaign, the Society worked to overcome "white coat silence" and to influence patient expectations by encouraging healthcare professionals to wear their white coats to public events and to educate the public about the importance of asking questions. Hairdressers provide information about the Society's resources to clients who mention that they or a loved one are receiving healthcare services. This use of service-industry workers to provide information to their clients has also been adopted in the UK by NHS Bradford and Airedale, which engaged taxi drivers to promote smoking cessation.

For further details, see:
Handbook Information: http://patientsikkerhed.dk/media/605495/patient_handbook2_.pdf
Just Ask Information: www.just-ask.dk, www.sporglos.sikkerpatient.dk
Relatives T-shirt campaign: www.sikkerpatient.dk/in-english/the-patient-involvement-programme/taking-it-to-the-streets.aspx
Danish Society for Patient Safety: www.patientsikkerhed.dk

DIPEx

The charitable organization DIPEx, in partnership with the Health Experience Research Group of the University of Oxford, UK, has published a robust online database of more than 25,000 video and audio clips, in which more than 2,000 patients and caregivers describe their health and healthcare experiences. The clips are catalogued by health topic, and are used as a resource by patients, families, healthcare providers, and policy-makers across all levels of engagement. The DIPEx website – **Healthtalkonline.org** – is used in various ways: to educate healthcare providers; to support patients and families in learning about their health, making informed decisions, and communicating effectively with health professionals; and to offer discussion triggers for an accelerated evidence-based co-design process, in which patients, families, and providers partner in quality-improvement efforts. The interviews are conducted and analyzed using rigorous qualitative research methods designed to obtain a full range of personal health experiences. The UK websites have been certified through The Information Standard, which reviews UK online health-information providers to validate that their information is clear, accurate, balanced, evidence-based, and up-to-date. A new organization – DIPEx International – has been created, and its members have launched similar sites in Canada, Germany, Japan, Republic of Korea, the Netherlands, and Spain.

For more details, see:
United Kingdom: www.healthtalkonline.org; www.youthhealthtalk.org;
Canada: www.healthexperiences.ca/en; Japan: www.dipex-j.org;
Republic of Korea www.healthstory4u.net; Germany www.krankheitserfahrungen.de;
The Netherlands www.pratenovergezondheid.nl; Spain www.dipex.es

WHO 7 Day Mother Baby mCheck Tool

In partnership with mothers, patient advocates and clinicians from around the world, the WHO's Patients for Patient Safety program developed a checklist tool – both paper-based and electronic – for use by mothers during the high-risk seven-day period after their babies are born. The tool is currently being implemented and tested. The tool focuses on key danger signs for both mother and baby during that crucial week, when the majority of maternal and newborn deaths occur. Using the checklist of evidence-based danger signs, mothers can ask themselves key questions, make informed decisions about the presence, severity and urgency of a problem, and decide when to access skilled care. The program also incorporates cell phone technology, so mothers can connect to an interactive automated system in their local language for additional advice on seeking care. The tool itself is a form of engagement, but the development of the tool also reflected patient engagement at all steps of the R&D process.

For further information, see:
www.who.int/patientsafety/patients_for_patient/mother_baby/tool/en/index.html

The Massachusetts General Hospital (MGH) Shared Decision Making Program in Primary and Specialty Care

MGH established a program for implementation of shared decision-making. The program, housed within a Health Decision Services Science Center, developed an innovative infrastructure for delivering decision aids to primary-care and specialty-care patients, as well as an effective educational program for clinicians on implementing shared decision-making in clinical practice. Relevant videos and booklets – detailed and high-quality decision aids – are available for 35 common health topics, including knee osteoarthritis, hip osteoarthritis, disc herniation, spinal stenosis, and the initiation of medications for hypertension, hyperlipidemia, depression, and high blood sugar.

To facilitate use of the decision aids, MGH created a streamlined process for professionals to prescribe the decision aids through the electronic medical record. More than 16,000 of the programs have been ordered by 650 clinicians to date.

The program also offers a unique educational curriculum on shared decision-making to 15 primary care practices (physicians, nurses, and office staff) and to 120 internal medicine resident physicians each year. They receive hands-on instruction on the use of the decision aids, with multiple opportunities to view the videos in whole or in part; this process increases clinicians' trust in the decision aids. Program data, including utilization and patient surveys, demonstrate the benefits of both the decision aids and the training program.

For further information, see: www.massgeneral.org/decisionsciences

ENGAGING ON THE INTERNET: ELECTRONIC ACCESS TO HEALTH RECORDS

Easy access to health information can promote patient engagement in care,[26] and a lack of access can be a significant obstacle to effective partnership, shared decision-making, and self-management. Many organizations are developing programs to enable patients to access and download their own medical records online.

One example is the **Blue Button program**. The Blue Button is a recognizable icon placed on many websites. The program was developed by the US Veterans Administration; it was subsequently transferred to the Office of the National Coordinator for Health Information Technology, and was made available to other organizations. As of October 2013, more than 500 organizations have publicly made one of two pledges: for data holders, the pledge is to "make it easier for individuals and their caregivers to have secure, timely, and electronic access to their health information" and to "encourage individuals to use this information to improve their health and their care"; and for non-data holders, the pledge is to "engage and empower individuals to be partners in their health through information technology."

For further details, see: www.healthit.gov/patients-families/pledge-info

Some organizations are also enabling patients to create their own measures of health, track that information online, and share it with their provider. One example is the electronic personal health record, **myhealthlocker**, developed for young people with mental health problems by South London and Maudsley Foundation Trust in the UK. Myhealthlocker makes use of interactive games to encourage participation. Feedback from the 130 current users has been positive with one participant commenting that "I feel that I am doing something positive and I am participating actively in my health recovery."

See: www.myhealthlockerlondon.nhs.uk

True Colours Program
True Colours is a self-monitoring and management system, developed in the UK, to gather, store and share data from patient-reported outcome measures in real-time, using simple technology in the form of the patient's own cell phone or computer. Messages are sent to patients to prompt them to respond to short validated questionnaires by text message, email, or internet. Software converts

those responses into easy-to-read graphs that are accessible, whenever needed, by the patients and their clinician. In addition to the standard questions, patients can write their own personalized questions. These might be used by patients to capture symptoms that are unique to them, to act as reminders (to take medication, for instance), or for self-motivation (to increase exercise, for example). True Colours also enables patients or clinicians to annotate the graphs with information such as medications taken, therapeutic interventions or general life events. These notes can be marked as private for the author, or be shared between patient and clinician.

A series of booklets, *Feeling Well with True Colours*, has been developed for different mental health disorders, to guide patients on how best to use True Colours as a self-management tool and thereby gain better control over their symptoms. There are now approximately 1000 patients using True Colours. Although originally developed for patients with mental health problems, the system has now been extended for use by people with long-term physical health conditions, including diabetes and osteoarthritis.

For further information, see: www.truecolours.nhs.uk

The mPedigree Network
The mPedigree Network is an organization that has developed and implemented technology to combat counterfeit medicine – a significant global health problem. Patients, providers, distributors, and manufacturers can utilize free text messaging to confirm the authenticity of a drug at the point of sale or transfer. mPedigree has successfully partnered with several pharmaceutical manufacturers to place an authenticity code on the product packaging; the code can then be verified utilizing this system. The system is currently operational in parts of Africa and India.

For further information, see: www.mpedigree.net/mpedigreenet

My Medication Passport
Inspired by suggestions from patient focus groups, the National Institute for Health Research collaborative in North West London (UK) worked with patients to develop My Medication Passport, a portable record of key information about patients' medications. The Medication Passport is aimed at empowering patients to take control of their medications, and at improving communication between patients, caregivers, and providers. Although the tool was originally developed for elderly patients, it is now being widely used by patients of all ages and conditions to maintain complete medication information across care settings. It is available both as a pocket-sized paper passport and through a smartphone application, and is distributed in inpatient, outpatient, and community settings. Approximately 30,000 copies of the paper tool have been distributed, and more than 2000 individuals from more than 37 countries have downloaded the application.

For details, see: www.clahrc-northwestlondon.nihr.ac.uk/research-projects/bespoke-projects/my-medication-passport

Stanford School of Medicine's Chronic Disease Self-Management Program

The School of Medicine at Stanford University in the US has developed a wide range of chronic-disease self-management programs, both in-person and online. Patients were actively involved in developing the curricula, which strive to enhance patients' self-efficacy in managing their conditions. Topics addressed include physical and emotional self-care strategies, medication use, effective communication, nutrition, and healthcare decision-making. Students who completed the six-week in-person course experienced fewer hospitalizations, and reported improved general health, symptom management, and communication with healthcare providers, as well as less fatigue and disability. Similarly, the six-week online course produced improved self-efficacy and health outcomes. Organizations in 22 countries have been licensed to offer the program. Also available are specialized online courses for back pain, diabetes, cancer, arthritis, and care-giving for loved ones with traumatic brain injury, post-traumatic stress disorder, dementia or diagnosed memory impairment.

For further information, see: http://patienteducation.stanford.edu/programs/cdsmp.html

RECOGNIZING THE ROLE OF FAMILY, FRIENDS, AND COMMUNITY IN HEALTHCARE

Many programs seek to harness the power of families, friends, and the community as partners in health and healthcare. Here are some good examples:

Family-Integrated Care in the Neonatal Intensive Care Unit enables parents to have 24-hour access to their premature infants, and in some cases to provide most of the care for them. The parents receive instruction and guidance from the staff. This program results in better outcomes for the newborns, such as increased weight gain and reduced length of stay; and it also reduces stress for the parents and builds their skills and confidence. Hospitals in Canada and Sweden have reported using this model. [27, 28]

Participatory learning and action groups have demonstrably improved maternal and newborn health in a variety of low-resource settings. One aim of the groups is to empower women through dialogue and problem-solving, rather than the distribution of health messages. "Phase 1 was to identify and prioritise problems during pregnancy, delivery, and post partum; phase 2 was to plan and phase 3 implement locally feasible strategies to address the priority problems; phase 4 was to assess their activities."[29] A meta-analysis of seven randomized controlled trials of learning and action groups, in Bangladesh, India, Malawi, and Nepal, determined that exposure to the groups resulted in a 37 percent reduction in maternal mortality and a 23 percent reduction in neonatal mortality.[30]

ORGANIZATIONAL DESIGN AND GOVERNANCE

Canadian Foundation for Healthcare Improvement

The Canadian Foundation for Healthcare Improvement (CFHI) collaborates with decision-makers to address difficult questions on organizing, financing, managing and delivering high-quality, affordable, patient- and family-centered healthcare for Canadians. Since September 2010, CFHI has supported 17 teams across Canada, whose task is to involve patients and their families in decisions about service design and delivery, or to increase their capacity for more meaningful engagement in such decision-making. While the projects had diverse aims and used multiple strategies to engage their clients (such as by advisory councils, surveys, and workshops), results confirm improved provider-patient communications (on pain management, for instance), the patient experience (for example, increased understanding of emergency department care processes), and other quality domains, including efficiency (for example, reduced mental-health admission time from 4.3 hours to 1 hour). Lessons learned are shared through papers and webinars; and CFHI's online resource center compiles additional tools to support patient and family engagement. An important part of the program is the evaluating of engagement activities; it helps participants to better understand what works and what doesn't.

For further information, see: www.cfhi-fcass.ca/WhatWeDo/PatientEngagement.aspx

Children's Hospital of Philadelphia (CHOP) Family-Centered Care (FCC) Program

One of the core aspects of CHOP's FCC Program is employing Family Consultants; these are paid positions for parents of current and former patients of CHOP. The Family Consultant role is to provide the family perspective in order to assist staff in the work they do. It might involve consulting with staff on specific cases, sitting on hospital steering committees, participating in root-cause analyses, reviewing and providing feedback on hospital policy and documents, assisting workgroups on specific projects, speaking to target groups on the family perspective, and participating in simulations to assist clinical and non-clinical staff in communicating with patients and families.

The Family Consultants have clearly defined roles, so each Consultant owns a component of the program and champions FCC work in that area. So a consultant might be involved in recruitment and orientation of the volunteer Family Partners Program, or in co-chairing the Family Advisory Council, or in supporting a research program that encompasses Patient Centered Outcomes Research. Family Consultants provide the family perspective and input on 34 hospital committees – strategic steering committees, committees on patient safety or ethics, communication teams, and many more. The Family Consultants also rely on a growing group of volunteer Family Partners – these are former patients, or their parents, caregivers, and support persons, and they provide feedback for specific projects, workgroups, staff education, documents and policies. This enables the Family Consultants, in assisting the staff, to share information that is diverse, robust and based on the experiences of many families. CHOP has worked to create a formalized process of orienting, training and providing ongoing mentoring to its Family Partners.

For further information, see: www.chop.edu

International Alliance of Patients' Organizations (IAPO) Patient Solidarity Day
On October 30 2013, patient advocacy groups in Africa partnered with WHO regional offices, health ministers and others to recognize patients as equal partners and to "improve lives through patient-centered healthcare." Events of several different types were held to commemorate the occasion, including public official commitments to a declaration on patient-centered healthcare, policy discussions, planning of health literacy and other programs, speeches, celebrations, and community health outreach events that offered screening, counseling, and education on various health issues. Solidarity Day unites patient advocacy organizations behind a common theme of engagement, irrespective of medical conditions or nationality. The first Patient Solidarity Day was held in Kenya in 2011, and the event has grown to include ten African countries in 2013 (Cameroon, Ghana, Kenya, Liberia, Malawi, Nigeria, South Africa, Uganda, Zambia, and Zimbabwe).

For further details, see: www.patientsorganizations.org/showarticle.pl?id=1670

Parents of Infants and Children with Kernicterus (PICK)
The PICK program exemplifies the power of partnerships between policy-makers and parents. PICK was created by a group of seven mothers whose newborns had been seriously affected by kernicterus – preventable brain damage resulting from untreated jaundice in newborns. PICK partnered with leading clinicians to create a research agenda, and developed materials to educate parents about the dangers of untreated jaundice and to teach them to recognize when to seek medical attention. PICK also partnered with several government and non-government policy-makers to heighten awareness and to embed kernicterus prevention in their programs. Through PICK's efforts, kernicterus was identified by US policy-makers as one of 27 healthcare events that should never occur.

For further information, see: http://pic-k.org

Dual Diagnosis Capability in Addictions Treatment (DDCAT) and Dual Diagnosis Capability in Mental Health Treatment (DDCMHT) of the US Substance Abuse and Mental Health Services Administration (SAMHSA)
SAMHSA supported the development of toolkits designed to help agencies bridge gaps in services for individuals with co-occurring mental and substance-use disorders. These tools are being used in more than 30 US states to transform the service delivery system, by addressing patient preferences through motivational interviewing. Providers are encouraged to connect with individuals with co-occurring disorders and their families, and collaborate with them through the assessment process, to enhance understanding of the individuals' needs, goals, and "stage of change, which

promotes patient-centered care." Treatment plans are individualized, patient-driven, and comprehensive; they are based on the individual's needs and self-identified goals, and they involve support from family groups and peers. Integrated treatment is provided through a multi-disciplinary team, and encompasses an individual's whole life, including family, social networks and community when possible. The program also includes staff training and continuing education. Agencies seek to involve people who have experience of living with co-occurring disorders; their roles may be as paid staff, volunteers, or program alumni.

DDCAT Information: www.samhsa.gov/co-occurring/DDCAT/index.html
DDCMHT Information: www.samhsa.gov/co-occurring/DDCMHT/index.html

RESEARCH

The Patient-Centered Outcomes Research Institute (PCORI)

PCORI is a private, non-profit organization, created and funded by US government legislation, that engages patients and families and those who care for them in the entire research process. They are involved in helping determine research topics and priorities, deciding what research gets funded, and participating in the design of research studies and in the dissemination of research findings to their respective communities. PCORI's mission is to "help people make informed healthcare decisions, and improve healthcare delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader healthcare community."

For further details, see: www.pcori.org

The Cochrane Collaboration

The Cochrane Collaboration is an international non-profit organization that conducts and publishes systematic reviews of the evidence for specific clinical interventions. The reviews are used by individuals and healthcare professionals to make effective healthcare decisions. Patients are actively involved in the development of the Cochrane summaries.

For further information, see: www.cochrane.org

The James Lind Alliance

The James Lind Alliance also engages patients and clinicians in priority-setting partnerships, for pursuing research related to treatment of particular clinical conditions.

For further information, see: www.lindalliance.org

OPPORTUNITIES FOR ACTION

This section highlights actions that health ministers, health system leaders, and the public can take to promote more effective engagement in each of the six areas of the Global Health Partnership Framework. As with the case studies, the proposed actions listed here are illustrative, not exhaustive. They are designed to inspire continued innovation, dialogue, and implementation. In each section, the highest-impact opportunities are highlighted first, in an effort to help health ministers choose where to start; but adoption of any of the opportunities for action will contribute to advancing health through engagement. Some of the opportunities for action reflect efforts that governments could undertake directly, while some depend on governments using their influence to instigate action from other partners.

The list of recommendations might look daunting in the face of competing priorities and limited resources. Of all the recommendations listed, the highest-impact opportunity for most countries is likely to be the first recommendation: improving health literacy in the adult population. To refine the recommendation even further, the enhancing of health literacy in women provides a unique opportunity to improve the health not only of women but of their families and communities.[31] Health literacy is already a focus of many independent national and regional efforts,[32] and it ties together the two top priorities identified by the world's citizens in the UN global survey: a good education and better healthcare.[33] Co-ordinating and intensifying health literacy efforts will help to build a firm foundation for patient, family, and community engagement at all levels.

EDUCATION

The recommendations in this section concentrate on building health literacy and partnership skills for patients, families and communities, as well as for health professionals and staff. In the traditional approach to healthcare, the professionals are the teachers, and the patients and families are passive recipients of information. Our recommendations reflect a different dynamic – one in which the patients, families, and community members do much of the teaching.

Educating patients and families

• **Develop and implement programs to improve the health literacy of the population, including enhancing primary and secondary education curricula to incorporate content related to physical and mental wellbeing, health literacy, statistical and risk literacy, self-care, and skills to enhance partnering with healthcare professionals**.

• Offer patients and families the opportunity to become more effective healthcare advocates, by hosting workshops from programs such as WHO Patients for Patient Safety or Project LEAD®, or by providing access to online resources such as courses from the Open School of the Institute for Healthcare Improvement.

Educating health professionals

- **Create patient and family faculty programs to educate healthcare professionals about the experience of illness and the patient and family perspective on what constitutes high quality care.**

- Upgrade health professional curricula and competencies by incorporating techniques for effective partnerships, such as motivational interviewing, shared decision-making and self-management support. The WHO has identified core competencies for caring for patients with chronic conditions, including specific competencies for patient-centered care and partnering.[34]

- Teach numeracy to healthcare professionals, so that they can accurately assess and communicate the statistical evidence related to treatment options.[35]

- Revise admission procedures for education programs for health professionals, to emphasize not just intellect but also the abilities to communicate and work in a team, since these abilities are crucial to effective engagement.

COMMUNITY HEALTH

At the community health level, people are not yet under the care of a healthcare worker or they are no longer being actively managed by a healthcare worker. For them, engagement efforts include: publicizing reliable sources of information about health and healthcare, optimizing decision-making and self-management, and providing guidance on when and how to seek professional care.

- **Offer evidence-based sources of health information and decision support tools to people through effective dissemination strategies such as electronic portals (for example, NHS Choices: www.nhs.uk/Pages/HomePage.aspx), cell phones, and alternative low-tech tools (paper-based, for instance).**

- **Partner with community organizations to improve health literacy, raise awareness of common health threats, and to enhance access to necessary health services; one good model here is mPedigree, which allows patients to immediately verify the authenticity of their medications.**

- Develop community education campaigns to lay the groundwork for partnership – for example, by setting expectations that health professionals want patients to speak up and raise questions and concerns; good models are the programs of the Danish Society for Patient Safety.

- Identify opportunities to partner with individuals and communities to raise awareness of situations warranting immediate medical attention; a good example is the WHO's mCheck initiative.

DIRECT CARE

During direct care, patients and families should be offered the opportunity to engage in shared decision-making and self-management to the best of their abilities. If any barriers to engagement have been erected by clinicians, either formally or informally, those barriers should be dismantled. The tools to facilitate engagement should be developed in partnership with patients and families, not on the basis of assumptions of what they need.

- **Set public expectations that every healthcare professional will routinely invite them to participate in informed decision-making, and will partner with patients and families to support their goals, as they define them.**

- **Promote self-management of medical conditions, through the use of effective materials and through coaching, support, and connections to community resources.**

- Using the advice and expertise of patients and families, develop and implement educational materials and decision aids that explain medical conditions and treatment options in ways appropriate for various levels of health literacy.

- Provide patients and anyone else they authorize with easy access to their personal health information, using online resources such as the Blue Button Initiative and written means such as the Medication Passport.

- Eliminate barriers to family participation in care – for example, by removing restrictions on hospital visiting hours and by inviting patients to include family members in routine discussions with healthcare workers; some research has shown that these measures have a positive impact on patient experience.[36]

- Develop peer mentor programs, such as the Tanzanian tuberculosis (TB) medication coaching program, which involves cured TB patients educating and coaching current TB patients in the community.[37]

ORGANIZATIONAL DESIGN AND GOVERNANCE

At this level, healthcare professionals should embed patient and family engagement in formal structures within the organization – structures such as advisor programs. Organizations should routinely require consultation with patients and families for certain tasks; for example, seeking their advice on the design of patient education materials is particularly important.

- **Engage patients and family members in developing and reviewing all communication and educational materials designed for patients and families, to ensure that they are relevant and clear.**

- **Mandate that all healthcare organizations will engage patients and families as partners in quality improvement, care design and redesign, and policy-setting through development of patient and family advisors and programs that have sufficient resources and training to be effective**.

PUBLIC POLICY

At this level, structures are needed for supporting engagement, such as a patient-centered measurement system, media partnerships that assist in effective public communication, and aligned incentives.

- **Directly engage the public in policy-making, using methods such as in-person consultation and placement on decision-making boards, and through the use of emerging methods such as social media and crowdsourcing.**

- **Examine and align incentives for the public, healthcare organizations and governmental agencies to promote engagement of the public; one model in this regard is the value-based purchasing system in the US, which pays hospitals in part on the basis of patient experience survey results.**

- Implement a standardized, valid, reliable and culturally appropriate measurement system for evaluating engagement, patient-reported outcomes, clinical measures, and patient experiences of care. Examples for consideration and adaptation include the CAHPS suite of patient experience surveys[38] and the Digital Health Scorecard for non-communicable diseases.[39]

- Partner with the media to develop standards for effective health reporting, such as the criteria used by Health News Review.[40]

RESEARCH

Research is an important driver of policy and practice. By integrating patients and families into the research process, you help not only to ensure the research's scientific validity but also to improve the participation of patients and families in clinical research and their use of the findings. The recommendations here focus on redirecting research toward questions of interest to the public, not just to scientists, and on translating findings into results that patients and families can readily use in decision-making. Research is also necessary to deepen our knowledge of effective engagement strategies, especially in different cultural contexts.

- **Require research funding entities to set the expectation that patients and families will be involved in all aspects of research activities they fund, including establishing study aims, design and methodology, and outcome measures.**

- **Continue to build the evidence base for effective engagement strategies across different cultures by integrating evaluation plans into the design of any engagement initiative.**

CONCLUSION AND IMMEDIATE NEXT STEPS

WISH represents a unique opportunity for advancing the global dialogue about engagement. To ensure that this robust discussion translates into a powerful impact on global health, we recommend that participating health ministers take the following three steps to accelerate engagement in their countries.

1. **Sign the Declaration on Engagement for Global Health** – both in-person at the Summit and online at www.wish-qatar.org/forums/patient-engagement. The declaration is a succinct statement of support for engagement at all levels of the Global Health Partnership Framework, coupled with a commitment to take action to implement one of the recommendations.

2. **Identify community partners, and sponsor jointly with them a Health Engagement Day**. Like the IAPO's Patient Solidarity Day in Africa, Health Engagement Day is an opportunity to demonstrate your commitment to engagement through a variety of activities, such as hosting a WHO Patients for Patient Safety workshop.

3. **Plan to participate in international Change Day on March 3 2014**. Change Day is a day when individuals publicly pledge to take action. Health ministers could use Change Day as an opportunity to invite patients, families, communities, and healthcare workers and staff to make personal commitments to engagement. The first Change Day was sponsored by the UK's National Health Service (NHS) on March 13 2013. On that day, more than 189,000 NHS staff made unique personal pledges to improve healthcare. This grassroots effort is being expanded globally in 2014.

Thank you for your work in advancing global health. Our hope is that this diverse international community will carry on learning together about the most effective ways of using engagement as a tool to improve health.

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NOTES

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