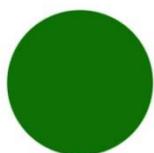


# The New Haven Recommendations on partnering with patients, families and citizens to enhance performance and quality in health promoting hospitals and health services



International Network of  
**H**Health  
**P**Promoting  
**H**Hospitals & Health Services



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## Introduction

Today, partnerships with patients and families are at the forefront of healthcare service delivery and quality improvement efforts globally (Conklin et al. 2010). Yet, within the International Network of Health Promoting Hospitals and Health Services (HPH Network), a systematic strategy to involve patients, families and citizens in health promoting healthcare is yet to be developed.

In comparison, the World Health Organization (WHO) with its Declaration of Alma Ata (WHO 1978), its Ottawa Charter for Health Promotion (WHO 1986) and its Declaration on the Promotion of Patients' Rights in Europe (WHO 1994) has played a decisive role in initiating and supporting partnerships with patients, families and citizens for decades. Accordingly, WHO has created a specific program area within their Patient Safety Program called Patients for Patient Safety, whose vision has been embedded within the London Declaration released in 2006 (WHO 2006). More recently, the WHO Strategy on People-centered and Integrated Health Services spells out clearly the importance of partnering with and involving patients and health service users to achieve health services that are responsive to and appropriate for people's needs (WHO 2015<sub>a</sub>). Finally, WHO has developed a formal position that defines patient and family engagement (PFE) as essential for patient safety and quality improvement efforts (WHO 2015<sub>b</sub>).

In line with these developments, personal and organizational health literacy has gained fundamental importance in WHO documents and elsewhere in order to facilitate patient and family engagement, especially as it pertains to patient information and communications (Brach et al. 2012; Pelikan & Dietscher 2014; WHO 2009, 2013). Face-to-face interactions between doctors and patients have been identified as the "heart of medicine" (Epstein et al. 1993) and as the main tool to realize patient-centered care and best health gain for patients (McDonalds 2016). For the German-speaking countries, also the concept of self-help friendly hospitals to facilitate the involvement of patient groups has become more and more important in the last century (Nickel et al. 2016; Trojan et al. 2014).

Furthermore, accrediting bodies are incorporating standards on how healthcare organizations partner with their target groups. Several (legal) documents such as the Declaration of Lisbon (WMA 1981), the European Charter of Patients' Rights (not legally binding) (Active Citizenship Network 2002) and the Universal Declaration on Bioethics and Human Rights (UNESCO 2005) emphasize the enhanced entitlement for patients and citizens in improving partnership with providers in the process of care. Moreover, legislation has been enacted in some states and countries, requiring hospitals and health service providers to have patient and family advisory councils (PFACs) (Massachusetts Commonwealth 189<sup>th</sup> Court 2009; van der Meide et al. 2015).

For these recommendations and according to definitions by WHO, partnering with patients, families and citizens in Health Promoting Hospitals and Health Services (HPH) requires that their needs and capabilities define direct service provision (micro-level), organizational structures and processes of hospitals and health services (meso-level) and the regulations and planning of healthcare delivery systems and policy (macro-level). Ultimately, patients and families as well as their advocates and more generally, citizens as potential health service users should be given more rights, a better voice and a genuine stake in decision-making on all three levels. Hospitals and health services should recognize and promote the essential role and centrality of patients, families and citizens in driving the improvement of quality and outcomes of value-based healthcare systems. This will involve a shift "out of the hands of those who give care and into the hands of those who receive it" (Berwick 2009).

As no commonly agreed upon definition of terms and concepts exists and to make these recommendations connective to different countries and healthcare systems, partnering with, involving and engaging patients, families and citizens will be used interchangeably in the following paragraphs.

### **Patient involvement within Health Promoting Hospitals and Health Services**

The International Network of Health Promoting Hospitals and Health Services (HPH Network) was initiated in 1990 by WHO Regional Office for Europe (WHO/Euro), following the first WHO-Model Project “Health and Hospital” in the late 1980s. Building on the foundation of the Ottawa Charter for Health Promotion (WHO 1986), the aim of the network was to support the development and implementation of health promotion in the specific organizational setting of hospitals and health services. Since then, the HPH Network has developed from mere conceptual considerations and pilot efforts, to a significant international movement comprising more than 900 member organizations. These mostly belong to one of more than 40 national or regional networks in five continents, and a small number of individual members in countries without recognized networks (Pelikan, Groene & Svane 2011). Since 2008, the HPH Network is an international association according to Swiss law. In 2010, a Memorandum of Understanding between the HPH Network and WHO/Euro was signed and an action plan was agreed upon.

According to WHO principles and recommendations (WHO 1978, 1986, 1994), involving patients, families and citizens was in the focus of the HPH Network from its very beginning. The first HPH policy paper, the Budapest Declaration on Health Promoting Hospitals (WHO 1991), emphasized that hospitals and health services should “Encourage an active and participatory role for patients according to their specific health potentials” (p.1). Later influential HPH policy documents such as the Vienna Recommendations on Health Promoting Hospitals (WHO 1997) as well as the official Constitution of the International Network of Health Promoting Hospitals and Health Services (HPH 2008) similarly have promoted and supported the relevance of addressing patients’ needs and involving them in healthcare. Accordingly, particular HPH Task Forces have taken up the specific needs and capabilities of different patient groups. Based upon the general HPH standards (Groene 2006), specific standards and self-assessment tools for particular target groups have been developed: for “Health Promotion for Children & Adolescents in and by Hospitals” (Simonelli et al. 2007), for “Age-friendly Health Care” (Chiou et al. 2010) and for “Migrant-friendly and Culturally Competent Healthcare” (Chiarenza et al. 2014).

While patients and the consideration of their needs and capabilities have been a fundamental principle within the international as well as national and regional HPH Networks and Task Forces since its beginnings, these recommendations aim to propose a comprehensive strategy for systematically and sustainably involving patients, families and citizens in health promoting healthcare.

### **Patient involvement in the United States of America**

In the United States of America, patient involvement has gained increased attention within the last few years. Especially Planetree, who was the local host of the 24<sup>th</sup> International HPH Conference in 2016, is one of the pioneers in furthering patient engagement. Since 1978, Planetree partners with healthcare organizations around the world and across the care continuum to transform the delivery

process of care. Based upon its more than 35 years of experience working with healthcare organizations, Planetree is uniquely positioned to represent the patient voice and advance how professional caregivers engage with patients and families (Frampton, Gilpin & Charmel 2003). It informs policy at a national level, aligns strategies at a system level, guides implementation of care delivery practices at an organizational level, and facilitates compassionate human interactions at a personal level. Accordingly, the first International HPH Conference that took place in the USA considered patient and family involvement within the main conference program and, thereby, has been a primary driver for these recommendations.

In addition to Planetree, established institutions like to the Institute of Medicine / National Academy of Medicine, the Center for Medicare & Medicaid Services, the American Hospital Association and others have embraced partnerships with patients as core to their improvement agendas in the USA. The Affordable Care Act, commonly referred to as Obama-Care, set aside funding for the Patient-Centered Outcomes Research Institute (PCORI). This organization requires research projects to focus on outcomes that are important to patients and further requires that patients and their families be actively involved in developing the research questions and carrying out the studies. The Veterans Healthcare Administration, the largest healthcare system in the USA, has embraced a new model of care focused on health promotion science combined with the patient's values and preferences around why their health is important to them as individuals. Additionally, healthcare organizations nationwide are using patient and family advocates and related councils as a foundational structure to engage patients and family members as partners in quality and process improvement, strategic planning, hiring and evaluation, staff training and to promote community building and align the organization's strategic priorities with what matters most to patients and families.

### **Purpose and Audience of the New Haven Recommendations**

The New Haven Recommendations identify specific strategies and actions that are required for effectively partnering with and involving patients, families and citizens. Thus, they specifically encourage the "active and participatory role for patients [families, and citizens]" (WHO 1991) to become a reality in re-oriented health services. By that, the recommendations relate to and support an important social movement on improving patient-, family- and citizen-centeredness in healthcare and their health gains with the opportunity to support new ways of thinking and engaging all stakeholders in the healthcare enterprise for this goal.

The New Haven Recommendations reach out to: (a) hospitals and other health services, especially to all members of the international, national and regional HPH Networks; (b) patients, families and citizens, their advocates and, more generally, representatives of health consumers and patient organizations; (c) practitioners in all kind of hospitals and health services as well as informal caregivers; (d) financiers and management of hospitals and health services; and (e) governments, politicians, policy makers and community stakeholders.

### **Structure and priorities of the New Haven Recommendations**

Since partnering with patients, families and citizens in healthcare can take many forms (Fung 2006), ranging from *individual* patient and family involvement (Charles, Gafni & Whelan 1997) – specifically

within the context of direct service provision – to *collective* involvement of patients, families and citizens such as partnering with patients or self-help groups on the organizational level and in planning healthcare delivery systems and policy (Frampton et al. 2013; Nickel et al. 2016; van de Bovenkamp, Trappenburg & Grit 2009) the recommended actions are structured following three priority levels:

- (a) enable patient and family involvement within direct service provision (micro-level)**
- (b) enable patient, family and citizen involvement among hospitals and health services (meso-level)**
- (c) enable patient, family and citizen involvement in planning healthcare delivery systems and policy (macro-level)**

Accordingly, the organizers and delegates of the 24<sup>th</sup> International HPH Conference stand up for a clearer and more cutting edge position on the essential role of patients as co-producers of their health. Patients, families and citizens should be enabled and empowered in defining health promotion goals and quality parameters from their own personal perspective, as well as in shaping the future practice and research agenda of the HPH Network and beyond. For that, patients, families and citizens need to be involved more consciously.

An appendix provides further information on each priority level, without asserting completeness. However, it has to be noted that the actions recommended will not be similarly applicable in all countries around the globe. Further adaptations may be required to implement them across a range of healthcare systems in different cultures and societies as well as for different target groups. For this reason, hospitals and health services are invited to adapt them to best fit their specific needs, capabilities and contexts.

## **Recommended Actions**

### **(a) Enable patient and family involvement within direct service provision**

As every patient is an individual, patient- and family-centered direct care requires actions in the following areas:

- i. raise awareness and capacity among patients and families to become active partners as co-producers in healthcare and in shared decision-making processes along the care pathway;
- ii. offer patient-centered communication and shared decision-making as the main tools to implement an active role of patients and families in their care;
- iii. promote the health of patients and families through individualized treatments / medicine, thus, considering that patients and families have different needs and expectations as well as diverging capabilities and conditions;
- iv. offer patients and families with severe problems effective and comprehensive care and treatment options by inter-professional teams that respect personal needs, goals and capabilities;
- v. further targeted support and interventions to encourage the involvement of members of vulnerable groups, particularly of children and adolescents, migrants, refugees and minorities, frail and older people, as well as people with dementia;
- vi. apply best practices of health literate or health literacy sensitive healthcare organizations to ensure that patients' and families' needs are adequately met and to strengthen the

effectiveness and efficacy of direct service provision, e.g. use plain language during communication with patients and families;

- vii. use inter-professional and inter-organizational communication supported by information and communication technologies (ICT) to ensure that patients' and families' needs, goals and capabilities are met throughout the whole care process.

Accordingly, the organizers and delegates of the 24<sup>th</sup> International HPH Conference would like to invite service providers as well as patients and families themselves to more systematically consider the possibilities of partnering with and involving patients and families in direct service provision to improve the performance and quality of health promoting healthcare and the wellbeing of patients. In order to achieve this, Table 1 in the attachment provides further information and selected examples.

### **(b) Enable patient, family and citizen involvement among hospitals and health services**

Patient, family and citizen involvement can only be put into practice through the adoption of adequate organizational structures and functions, processes and technologies that create transparent and inclusive cultures. Focused institutional capacity-building with particular attention given to the role of patient and family advocates is necessary. To achieve this, the following main actions for the next decade are recommended:

- i. make patient, family and citizen involvement as well as targeted communication an organizational core value and adapt care processes and incentives to promote patient-centered communication;
- ii. set up governance structures and develop a leadership culture that values and facilitates patient, family and citizen involvement at every level of the organization and in all patient-related processes and structures, e.g. through establishing patient and family councils within safety committees or hospital boards;
- iii. when recruiting and employing new staff, ensure that they are oriented and trained in how the organization facilitates patient, family and citizen involvement;
- iv. partner with patients, families and citizens in the implementation and discussion of the results of quality and patient safety improvement / health promotion projects and thereby, develop a common definition of future priorities for resource allocation;
- v. involve patients, families and citizens in the assessment and decision-making related to health-related information and communication technologies;
- vi. build up the consciousness, capacities and abilities of health professionals as well as other staff, especially of those who are in direct contact with patients and families, to offer effective access, identification of needs and capabilities, adequate communication and shared decision-making as well as targeted treatments by providing education and specific training programs for staff;
- vii. facilitate networking of staff with other organizational departments, also those responsible for specialized and non-medical care, including the social sector, volunteers and civic associations in the community;
- viii. invite patients and families to share their stories e.g. within team meetings, during training courses, as guest lecturers, during simulated learning, as a mentor etc.;
- ix. consider approaches that encourage the initiation and support of self-help initiatives to benefit patients, families and citizens.

The organizers and delegates of the 24<sup>th</sup> International HPH Conference request the commitment and support of the various involved stakeholders to put these actions into practice. Table 2 in the appendix provides further information as well as selected examples.

### **(c) Enable patient, family and citizen involvement in planning healthcare delivery systems and policy**

Hospitals and health services do not act in a vacuum. Their possibilities of partnering with and involving patients, families and citizens are strongly influenced by their environment, especially by legal and organizational frameworks that are largely shaped by health policy and healthcare financing mechanisms. Accordingly, the following actions are recommended:

- i. consider the impact of public policies and legislation on patient, family and citizen involvement, with particular attention to patient and family advocates;
- ii. develop governance, policy and infrastructure that give patient and family advocates more rights to shape healthcare delivery and provide accountability frameworks;
- iii. make the assessment of patient, family and citizen involvement and targeted communication a priority in quality management and accreditation systems;
- iv. allocate resources for enabling and empowering patient and family advocates, e.g. resources for specific trainings and other support including new technologies;
- v. provide fair and adequate financial resources for healthcare providers to be able to deliver patient-, family- and citizen-centered information, communication and care;
- vi. involve advocates of patients, families and citizens when analyzing patient harms and adverse events in healthcare;
- vii. support planning, evaluation and research activities that involve patients, families and citizens, especially from marginalized service-users, in the development of research questions, methods and reporting of healthcare research (participatory research as well as qualitative and mixed-methods);
- viii. make research findings accessible and understandable to patients, families and citizens, e.g. provide incentives to publish “common language” abstracts in reports and any other publications that patients, families and citizens can understand and, therewith, begin to break down the silos between stakeholders in healthcare.

By this, these recommendations follow current developments in healthcare as well as a recent call of 80 health research scientists who emphasized the relevance of qualitative research in a letter written to the British Medical Journal decrying the stated bias toward publishing quantitative studies at the expense of good qualitative research (Greenhalgh et al. 2016). The organizers and delegates of the 24<sup>th</sup> International HPH Conference call upon all relevant stakeholders to commit to putting these actions into practice. For further details, see Table 3.

### **Conclusions**

To ensure that direct service provision, structures and processes of hospitals and health services and, more broadly, healthcare delivery systems and policy become more patient-, family- and citizen-centered, the organizers and delegates of the 24<sup>th</sup> International HPH Conference recommend an active partnership with and involvement of patients, families and citizens on all levels of healthcare. This will

require new skills in listening, learning and partnering among patients, families, citizens and staff, but there are numerous organizations and toolkits to show the way forward. The HPH Network, its members and partners are therefore encouraged to collaborate with international (patient) organizations and professional networks, that develop and train these new skills, such as Planetree, the European Patients Forum (EPF), the Collaborative Action Research Network (CARN), the American Association for Communication in Healthcare (AACH), the European Association for Communication in Healthcare (EACH), the International Union of Health Promotion and Education (IUHPE), the Institute of Medicine, National Academy of Sciences (IOM/NAM) and many others.

As a next step, the HPH Network should establish a working group to systematically spread the message of these recommendations among different stakeholders by various channels and media. In addition, the development of standards and indicators for a self-assessment tool on organizational sensitivity to involving and partnering with patients, families and citizens in healthcare should be started. Such a tool would facilitate the integration of these recommendations in ongoing quality and health promotion efforts. Furthermore, such a tool can help to systematically enable patient, family and citizen involvement in hospitals and health services, foremost among members of the HPH Network.

### **Development process**

The New Haven Recommendations were prepared and developed by major actors and participants of the 24<sup>th</sup> International HPH Conference, New Haven (CT), USA, June 8-10, 2016 hosted by Planetree. These included representatives of Planetree and HPH (Governance Board, WHO Collaborating Centre for Health Promotion in Hospitals and Health Care, Secretariat, Task Forces, coordinators from networks in Asia, Australia, USA, Europe), of WHO/EURO and the Austrian Ministry of Health and Women's Affairs as well as renowned patient and family advocates from the USA and Canada, and several practitioners and researchers in the field.

Utilizing multiple participatory processes, the recommendations were elaborated over a period of four months with input of the above-mentioned participants. The final version of the recommendations was approved during the meeting of the HPH General Assembly at the 24<sup>th</sup> International HPH Conference in New Haven (CT) and further edited after the conference.

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## Appendix: Selected actions and further information

Table 1: Overview of selected actions to partner with and involve patients and families within direct service provision (micro-level)

Selected actions	For further information
<p><b>Follow the Planetree model to ensure patient- and family-centered care</b></p>	<ul style="list-style-type: none"> <li>- Planetree created a set of person-centered standards for excellence, the Patient-Centered Designation program, and sponsors an awards program that recognizes innovation in healthy communities programming and effective approaches to caring for caregivers. For further information about Planetree see: <a href="http://planetree.org/approach/#designation/">http://planetree.org/approach/#designation/</a></li> <li>- For an overview of the Planetree model, see the presentation by Patrick A. Charmel (Chairman of the board of Planetree) given during the 24<sup>th</sup> International HPH Conference: <a href="http://www.hphconferences.org/connecticut2016/proceedings.html">http://www.hphconferences.org/connecticut2016/proceedings.html</a></li> <li>- For an example on how the Planetree model is enacted, have a look at Griffin Hospital, which was one of the first Planetree hospitals and has a robust employee fitness and well-being program as well as community health promotion initiatives: <a href="http://www.griffinhealth.org/">http://www.griffinhealth.org/</a></li> <li>- Planetree has also created resources specifically for patients and families, designed to familiarize them with a range of ways they can actively engage as partners on their own care team. Examples are: <a href="http://planetree.org/wp-content/uploads/2015/08/Planetree50Ways.pdf">http://planetree.org/wp-content/uploads/2015/08/Planetree50Ways.pdf</a> <a href="http://planetree.org/wp-content/uploads/2015/08/PCCAM-Doctor.pdf">http://planetree.org/wp-content/uploads/2015/08/PCCAM-Doctor.pdf</a> <a href="http://planetree.org/wp-content/uploads/2015/08/PCCAM-Hospital.pdf">http://planetree.org/wp-content/uploads/2015/08/PCCAM-Hospital.pdf</a></li> <li>- Other organizations which support patient- and family-centered care in the USA are e.g. the Patient and Family Centered Care Partners (PFCC partners) who offer support to build a community of healthcare providers, administrators, and patients and families to improve direct service provision: <a href="https://pfccpartners.com/">https://pfccpartners.com/</a></li> <li>- For involving patients and family within <u>ambulatory care</u>, there are recommendations available at: <a href="http://www.ipfcc.org/pdf/GettingStarted-AmbulatoryCare.pdf">http://www.ipfcc.org/pdf/GettingStarted-AmbulatoryCare.pdf</a></li> <li>- WHO offers education and assistance to develop Patients for Patient Safety networks. More information can be found at: <a href="http://www.who.int/patientsafety/patients_for_patient/en/">http://www.who.int/patientsafety/patients_for_patient/en/</a></li> </ul>
<p><b>Use health literacy measures to facilitate patient- and family centered care</b></p>	<ul style="list-style-type: none"> <li>- The CAHPS® Item Set for Addressing Health Literacy helps to measure how well information within direct service provision is communicated to patients by a healthcare professional from a patients' perspectives. This is available at: <a href="https://cahps.ahrq.gov/surveys-guidance/item-sets/literacy/2311_About_Health.pdf">https://cahps.ahrq.gov/surveys-guidance/item-sets/literacy/2311_About_Health.pdf</a></li> <li>- To assess practices and make changes, consider the Health Literacy Universal Precautions Toolkit of the Agency Healthcare Research and Quality. The tool is available at: <a href="http://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthliteracytoolkit.pdf">http://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthliteracytoolkit.pdf</a></li> <li>- The Health literacy environment of hospitals and health centers by Rudd and Anderson (2006) helps to improve communication and to reduce health literacy demands for patients: <a href="https://cdn1.sph.harvard.edu/wp-content/uploads/sites/135/2012/09/healthliteracyenvironment.pdf">https://cdn1.sph.harvard.edu/wp-content/uploads/sites/135/2012/09/healthliteracyenvironment.pdf</a></li> </ul>
<p><b>Follow the standards for health literate healthcare organizations and apply the self-assessment tool</b></p>	<ul style="list-style-type: none"> <li>- The WHO-CC-HPH and the Austrian HPH Network have jointly developed a set of 9 standards, 22 sub-standards and 160 items as well as a self-assessment tool (currently only in German, English translation is in progress) to determine the (organizational) health literacy of hospitals. These documents are available at: <a href="http://www.ongkg.at/downloads-links/downloads.html#c3513">http://www.ongkg.at/downloads-links/downloads.html#c3513</a></li> <li>- Rudd et al. have defined 10 attributes of health literate healthcare organizations. Organizations that embody these attributes enable patients to access and benefit optimally from the range of services. Have a look at: <a href="http://www.ahealthyunderstanding.org/Portals/0/Documents1/IOM_Ten_Attributes_HL_Paper.pdf">http://www.ahealthyunderstanding.org/Portals/0/Documents1/IOM_Ten_Attributes_HL_Paper.pdf</a></li> </ul>

Table 2: Overview of selected actions to partner with and involve patients, families and citizens among hospitals and health services (meso-level)

Selected actions	For further information
<p><b>Establish patient and family advisory councils</b></p>	<ul style="list-style-type: none"> <li>- In the USA, Planetree, Patient and Family-Centered Care Partners, the National Academy of Medicine and the Institute for Patient- and Family-Centred Care (IPFCC) provide guidelines and resources on Creating patient and family advisory councils. These are available at: <a href="http://www.ipfcc.org/advance/Advisory_Councils.pdf">http://www.ipfcc.org/advance/Advisory_Councils.pdf</a> <a href="http://patient-centeredcare.org/">http://patient-centeredcare.org/</a> <a href="http://nam.edu/wp-content/uploads/2015/08/PFLN-Resource-Compendium_21aug15.pdf">http://nam.edu/wp-content/uploads/2015/08/PFLN-Resource-Compendium_21aug15.pdf</a></li> <li>- The IPFCC also provides a mini toolkit on Partnering with Patients and Families to Enhance Safety and Quality, which can be accessed via: <a href="http://www.ipfcc.org/tools/Patient-Safety-Toolkit-04.pdf">http://www.ipfcc.org/tools/Patient-Safety-Toolkit-04.pdf</a></li> <li>- Documents on how to get started with patient- and family-centered care in hospitals that include self-assessment tools for hospital leaders, staff as well as patient and family leaders, can be found at: <a href="http://patient-centeredcare.org">http://patient-centeredcare.org</a> <a href="http://www.ipfcc.org/pdf/getting_started.pdf">http://www.ipfcc.org/pdf/getting_started.pdf</a></li> <li>- The Netherlands and the UK have developed patient and family councils which have been strongly supported on the national political level down to local practice: van der Meide H, Olthuis G, Leget C (2014). Patient participation in hospital care: how equal is the voice of the client council? <i>Health Care Analysis</i>, DOI: 10.1007/s10728-014-0271-x</li> <li>- Insights of a qualitative study about facilitators of and barriers to patient-centered care in the USA can be found at: Luxford K, Gelb Safran D, Delbanco T (2011). Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. <i>International Journal for Quality in Health Care</i>, DOI: 10.1093/intqhc/mzr024</li> </ul>
<p><b>Follow the criteria for self-help friendly hospitals</b></p>	<ul style="list-style-type: none"> <li>- For countries such as Germany or Austria, which are characterized by a fragmented, Bismarckian healthcare system, a top-down approach as embraced in The Netherlands and UK is not feasible. That is why the self-help friendliness approach was developed. Further information about the self-help friendliness approach see: Nickel S, Trojan A, Kofahl C (2016). Involving self-help groups in health-care institutions: the patients' contribution to and their view of 'self-help friendliness' as an approach to implement quality criteria of sustainable co-operation. <i>Health Expectations</i>, DOI: 10.1111/hex.12455. Trojan A, Nickel S, Kofahl C (2014). Implementing 'self-help friendliness' in German hospitals: a longitudinal study. <i>Health Promotion International</i>, DOI: 10.1093/heapro/dau103.</li> <li>- Evidence that the self-help-friendliness approach is feasible, transferable and a helpful measure for promoting patient-centered care is provided in the following: Kofahl C, Trojan A, von dem Knesebeck O, Nickel S (2014). Self-help friendliness: A German approach for strengthening the cooperation between self-help groups and health care professionals. <i>Social Science &amp; Medicine</i>, DOI: 10.1016/j.socscimed.2014.06.051.</li> <li>- Considering the collaboration among hospitals and self-help groups, Forster et al. (2013) show that hospitals "support self-help activities" rather than enable the "involvement of representatives of different self-help groups in planning and strategy development" and, therefore, suggest a step-wise approach to move from a complementary role of self-help groups to a more participatory role: Forster R, Rojatz D, Schmied H, Pelikan JM (2013). Selbsthilfegruppen und Gesundheitsförderung im Krankenhaus – eine entwicklungsfähige Allianz für Gesundheit. [Self-help groups and health promotion in hospitals – a viable alliance for health]. <i>Prävention &amp; Gesundheitsförderung</i>, DOI: 10.1007/s11553-012-0364-z</li> <li>- To learn more about the characteristics of self-help groups, have a look at: Borkman T (1976). Experiential knowledge: a new concept for the analysis of self-help groups. <i>Social Service Review</i>, 50(3): 445–456.</li> </ul>

Selected actions	For further information
<p><b>Education and capacity-building of healthcare professionals as well as leadership</b></p>	<ul style="list-style-type: none"> <li>- To prepare professionals as well as leadership for involving and partnering with patients and families, see the document “Partnering with patients and families to design a patient- and family-centered healthcare system – recommendations and promising practices” (IPFCC 2008, chapter 4 &amp; 5) which is available at: <a href="http://www.ipfcc.org/pdf/PartneringwithPatientsandFamilies.pdf">http://www.ipfcc.org/pdf/PartneringwithPatientsandFamilies.pdf</a></li> <li>- The American Hospital Association (AHA) has developed resources for administrative and governance leaders that would be useful in the curricula for healthcare leaders and in continuing education programs. For further details, see <a href="http://www.aha.org/advocacy-issues/quality/strategies-patientcentered.shtml">http://www.aha.org/advocacy-issues/quality/strategies-patientcentered.shtml</a></li> <li>- The Planetree patient-centered care retreat combines skill-development with inspiration and team-building to train staff. It offers tools and support for promoting compassion among staff as well as leaders, and for embedding compassionate human interactions into organizational processes and practices. For further details see: Guastello S, Frampton SB (2014). Patient-centered care retreats as a method for enhancing and sustaining compassion in action in healthcare settings. <i>Journal of Compassionate Health Care</i>, DOI: 10.1186/s40639-014-0002-z.</li> </ul>
<p><b>Follow a human rights based approach</b></p>	<ul style="list-style-type: none"> <li>- To advance the respect, protection and fulfilment of children’s rights within hospitals and health services, the HPH task force on Health Promotion for Children &amp; Adolescents in &amp; by Hospitals provides a manual as well as several tools which can be accessed at: <a href="http://www.hphnet.org/index.php?option=com_content&amp;view=article&amp;id=1551:hp-for-children-a-adolescents-in-a-by-hospitals-&amp;catid=20">http://www.hphnet.org/index.php?option=com_content&amp;view=article&amp;id=1551:hp-for-children-a-adolescents-in-a-by-hospitals-&amp;catid=20</a></li> </ul>

Table 3: Overview of selected actions to partner with and involve patients, families and citizens in planning healthcare delivery systems and policy

Selected actions	For further information
<p><b>Make patient and family involvement a requirement for funding</b></p>	<ul style="list-style-type: none"> <li>- The Patient-Centred Outcomes Research Institute (PCORI) puts strong emphasis on involving patients and the broader healthcare community in all the work that is funded. Furthermore, they provide awards to encourage partnerships with patients in research activities. For general information see: <a href="http://www.pcori.org">http://www.pcori.org</a></li> <li>- At the PCORI Engagement Rubric, a framework for engaging patients and other partners in the research process, can be found: <a href="http://www.pcori.org/sites/default/files/Engagement-Rubric.pdf">http://www.pcori.org/sites/default/files/Engagement-Rubric.pdf</a></li> <li>- Involvement of the target groups is also a prerequisite for funding of research projects by the Austrian Health Promotion Foundation (Fonds Gesundes Österreich): <a href="http://info.projektguide.fgoe.org/fileadmin/redakteure/downloads/hilfestellungsdownloads/2015/fgoe_leitfaden_projektfoerderung.pdf">http://info.projektguide.fgoe.org/fileadmin/redakteure/downloads/hilfestellungsdownloads/2015/fgoe_leitfaden_projektfoerderung.pdf</a></li> </ul>
<p><b>Put more emphasis on qualitative research</b></p>	<ul style="list-style-type: none"> <li>- Examples of qualitative research studies with regard to health promotion and HPH can be found at:            Lee CB, Chen MS, Wang Y (2014) Barriers to and facilitators of the implementation of health promoting hospitals in Taiwan: A topdown movement in need of ground support. <i>The International Journal of Health Planning and Management</i>, 29, DOI: 10.1002/hpm.2156.            Wieczorek CC, Schmied H, Dorner TE, Dür, W (2015) The bumpy road to implementing the Baby-Friendly Hospital Initiative in Austria: A qualitative study. <i>International Breastfeeding Journal</i>, 10(3), DOI: 10.1186/s13006-015-0030-0. Available at: <a href="http://internationalbreastfeedingjournal.biomedcentral.com/articles/10.1186/s13006-015-0030-0">http://internationalbreastfeedingjournal.biomedcentral.com/articles/10.1186/s13006-015-0030-0</a>.</li> <li>- For further information on qualitative research see:            Ritchie J, Lewis J (ed.). <b>Qualitative research practice. A guide for social science students and researchers</b>. London: Sage Publications; 2009            Patton MQ (ed.). <b>Qualitative research &amp; evaluation methods</b>. 3<sup>rd</sup> ed. Thousand Oaks, California: Sage Publications; 2002</li> </ul>
<p><b>Further mixed-method approaches</b></p>	<ul style="list-style-type: none"> <li>- John W. Creswell of the University of Nebraska elaborates upon mixed method approaches in his book “Research Design: Qualitative, Quantitative and Mixed Methods Approaches” (2<sup>nd</sup> edition) published by Sage Publications. A limited version is available at: <a href="http://isites.harvard.edu/fs/docs/icb.topic1334586.files/2003_Creswell_A%20Framework%20for%20Design.pdf">http://isites.harvard.edu/fs/docs/icb.topic1334586.files/2003_Creswell_A%20Framework%20for%20Design.pdf</a></li> <li>- The <i>Journal of Mixed Methods Research</i> (JMMR) publishes empirical, methodological, and theoretical articles about mixed methods research across the social, behavioral, health, and human sciences: <a href="http://mmr.sagepub.com/">http://mmr.sagepub.com/</a></li> <li>- Esch et al. use a mixed methods approach to evaluate the engagement of patients through open notes in the USA:            Esch T, Mejilla R, Anselmo M, Podtschaske B, Delbanco T, Walker J (2016). Engaging patients through open notes: an evaluation using mixed methods. <i>BMJ Open</i>, DOI: 10.1136/bmjopen-2015-010034.</li> <li>- In the article, Rabeharisoa provides an example how patient organizations can be active in research activities concerning them:            Rabeharisoa V (2003). The struggle against neuromuscular diseases in France and the emergence of the “partnership model” of patient organizations. <i>Social Science &amp; Medicine</i>, DOI: 10.1016/S0277-9536(03)00084-4.</li> <li>- In Canada, researchers and practitioners collaboratively developed a comprehensive tool aimed at three respondent groups to evaluate public and patient engagement:            Abelson J, Li K, Wilson G, Shields K, Schneider C, Boesveld S (2015). Supporting quality public and patient engagement in health system organizations: development and usability testing of the Public and Patient Engagement Tool. <i>Health Expectations</i>, DOI: 10.1111/hex.12378</li> </ul>