NATIONAL QUALITY FORUM

Meeting Summary

Patient and Family Engagement Action Team

The National Quality Forum (NQF) convened a web meeting of the Patient and Family Engagement Action Team and the public on August 5, 2014. An online archive of the meeting is available by clicking here.

Action Team Member Attendance

Patient and Family Engagement Action Team Members	
Name	**Organization**
Susan Frampton	*Planetree*
Pat Mastors	*Patient Voice Institute*
Mary Clough	*University of Minnesota Medical Center*
Ted Eytan	*Kaiser Permanente*
Richard Hanke	*Consumer Representative, REH & Associates*
Libby Hoy	*Person and Family Centered Care Partners*
Carol Levine	*United Hospital Fund*
Carol Wahl	*Good Samaritan Hospital*
Jonathan Welch	*Harvard Medical School*

Welcome and Review of Meeting Objectives

Led by Susan Frampton, Planetree, Action Team Co-Chair

Dr. Frampton welcomed the group and reviewed the meeting objectives, which were to:

- Present the *Patient Passport* model
- Provide examples of dissemination strategies
- Discuss specific ways that patients, clinicians, and health administrators can use the *Patient Passport* in their life and work

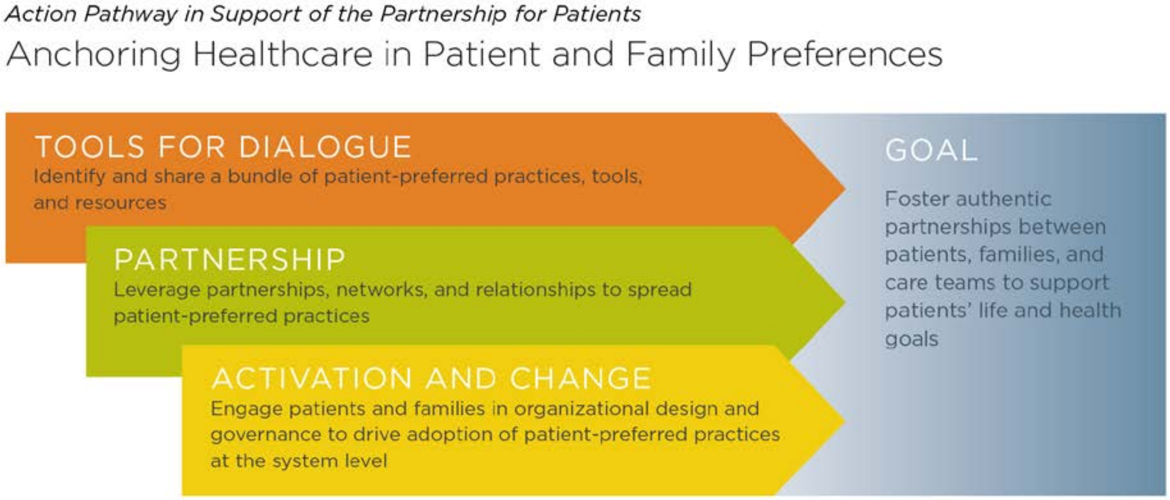
Overview of Patient and Family Engagement and the Action Team's Work

Led by Susan Frampton, Planetree, Action Team Co-Chair

Dr. Frampton opened the webinar by providing some background and framing for the work of the Patient and Family Engagement (PFE) Action Team. She reminded the audience that patient and family engagement is connected to the National Quality Strategy priority area of Person- and Family- Centered Care and provided a definition of patient and family engagement that emphasized the partnership between patients, families, and health care providers. NQF's PFE Action Team is part of the Partnership for Patients' initiative, and Dr. Frampton reviewed the Partnership for Patients areas of focus for authentically engaging patients, and the five dimensions of patient and family engagement it has been tracking (e.g., having a discharge planning checklist and bedside reporting with patients and family members).

She highlighted the action team members and reminded the audience of the action pathway that the team developed earlier in the year, which includes the goal and strategies (Figure 1) it has been working towards.

Figure 1: Patient and Family Engagement Action Pathway



The *Patient Passport* Model

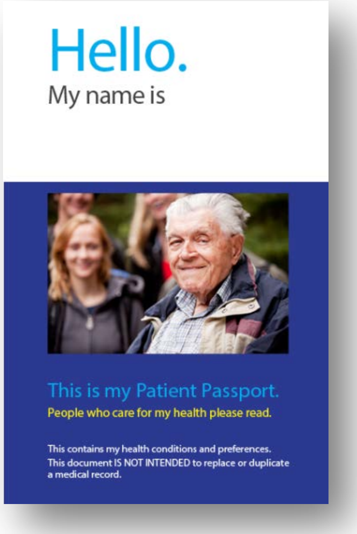
Led by Pat Mastors, Patient Voice Institute, Action Team Co-Chair

The first strategy of the action team was to identify and share patient-preferred practices, tools, and resources. To use this strategy effectively in reaching the action team goal, it developed a prototype or model *Patient Passport*, a communications tool to help patients express their needs and preferences with their healthcare providers at the point of care. Ms. Mastors explained the process the action team underwent to create this tool, by starting with other similar models (e.g., Patient Passports – called "My Healthcare Passports" – used with the learning disability population in the United Kingdom, and a Patient Passport developed for the Mattel Children's Hospital UCLA in collaboration between parents of medically complex children and the emergency department clinicians). The action team spent its second in-person meeting examining many different models, and prioritizing the domains of what a comprehensive, US model could look like that would be appropriate for a general population but could still be adapted at the local level for specific demographics.

Ms. Mastors explained that the action team settled on these domains as essential to its Patient Passport prototype:

- Patient Identification (name, photo, preferred language)
- Critical Health Information (e.g. allergies, medications, disability, relevant care plans, primary contact, caregiver information)
- Health Team (PCP, other doctors)
- Health History and Goals (significant health events, previous hospitalizations, coping with my health conditions – good days and bad days, health goals for when I get out of the hospital)
- What I Need While I'm Here (major concerns, what would make me feel comfortable, what I need extra help with, etc.)
- Personalized Photo
- Discharge (what to do when I get home)
- Advance Care Directives and End of Life Preferences

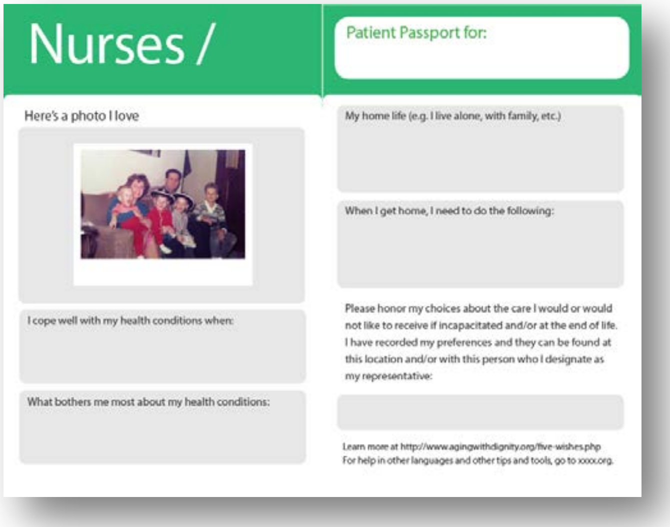
She presented visual images of the prototype and the potential impact of the passport on patients, physicians, and nurses:



Hello.
My name is

This is my Patient Passport.
People who care for my health please read.

This contains my health conditions and preferences.
This document IS NOT INTENDED to replace or duplicate a medical record.



Nurses /

Patient Passport for:

Here's a photo I love

I cope well with my health conditions when:

What bothers me most about my health conditions:

My home life (e.g. I live alone, with family, etc.)

When I get home, I need to do the following:

Please honor my choices about the care I would or would not like to receive if incapacitated and/or at the end of life. I have recorded my preferences and they can be found at this location and/or with this person who I designate as my representative:

Learn more at http://www.agingwithdignity.org/five-wishes.php
For help in other languages and other tips and tools, go to xxxx.org.

For **patients**, the passport has the potential to change the quality of interactions inside the hospital – with the triage nurse, the bedside nurse, and the attending physician by helping them understand your needs and preferences

The passport allows **physicians** to see at a glance what conditions the patient has been diagnosed with, what medications he or she is taking, what doctors are treating the patient, the patient's health goals, preferences for treatment, and what has and hasn't worked to treat the patient's health conditions.

The *Patient Passport* helps patients tell **nurses** what they need special help with (e.g., eating, dressing, walking), what helps them cope with their health conditions, what their home life is like, and if the patient has any care plans or end of life preferences in the event they become incapacitated or cannot make decisions for themselves. The passport helps make it easier to care for more than just physical needs – it specifically addresses emotional, psychological, and spiritual as well as the important physical components of care.

Opportunities for Dissemination

Led by Susan Frampton

Dr. Frampton shared two opportunities, one underway and one upcoming, to pilot the *Patient Passport*. This represents the next important strategy in the action team pathway – using partnerships to disseminate and spread patient-preferred practices. Griffin Hospital in Connecticut is incorporating the passport into a community-wide patient-family activation initiative aimed at developing shared decision-making partnerships between patients and their physicians; increasing engagement and activation of patients and families; improving population health, and ensuring end-of-life care that honors patient preferences.

The St. Vincent Indianapolis health system is also planning to pilot the *Patient Passport*, most likely using its newly launched patient portal to connect to an app of the passport that is being launched in September.

The action team is encouraging widespread use of the tool which could potentially lead to outcomes such as fewer hospital stays/days, fewer adverse events, increased patient satisfaction and activation, and an increased sense of connectedness and efficacy in hospital staff.

Partnering with Patients, Clinicians, and Health Administrators: Discussion and Q&A

Led by Pat Mastors and Susan Frampton

Pat Mastors and Susan Frampton led discussion and Q&A about how patients, clinicians, and health administrators can begin to use the *Patient Passport* in their lives and work, and solicited input about ways to improve it and make it as practical and impactful as possible. There were a number of public comments by phone and over 50 chat comments and questions. A number of attendees shared lessons they have learned by implementing similar patient engagement or education initiatives, which was useful feedback for the action team. These were some of the implementation issues raised:

- Platform – paper vs. electronic – and how the passport will work with personal health records and EHRs
- Frontline staff education/sensitization; one suggestion was to have staff fill out the passport to familiarize themselves with it
- Expansion / adaptation of the passport for specific demographics, such as non-English speakers, children, the mental health population, etc.
- The role of the family and caregivers in completing or utilizing the passport
- Testing of the passport for impact on outcomes

In follow-up to the webinar, the following questions and answers were sent to all webinar attendees to address the common themes that were raised by attendees.

Question: *What is the role of the family/caregiver in the Patient Passport?*

Answer: The PFE Action Team's passport prototype was significantly influenced by the UK models used for a learning disability population, which have similar needs to fragile patients who rely heavily on caregivers and family to help them. The parts of the passport that demonstrate this in particular are the beginning (triage) section, which is intended to help health staff see who the primary caregivers/family are and their role in relationship to the patient. Also, the "what I need help with while I'm here" section is a place to spell out special needs, such as memory loss, and the need to have family/caregivers close by during the care process,.

The passport is intended to be a communication tool between the patient and provider. If the patient cannot communicate, a different version may be required. However, if the patient wants and needs to communicate the importance of their family/caregivers in their life and healthcare, the passport is intended to help them do that. We welcome additional ideas for how it can do this.

Question: *Is the intention to have one "universal" passport for the whole country or modified versions for different health systems?*

Answer: The *Patient Passport* model as presented on the webinar is meant to be a prototype--not a one-size-fits-all. Different populations and health systems may need local adaptation to meet their needs. However, the PFE Action Team hopes that the essential domains as presented on the webinar (slide 11) are reflected in each version.

Question: *Has the Patient Passport been tested with specific populations or had outcomes measured?*

Answer: Not yet. Action team members are beginning to pilot the *Patient Passport*, both in hard copy and in electronic version, which should yield some interesting data points. We encourage others who are interested in testing or piloting the passport to let us know so we can continue to spread patient-preferred practices through use of the passport model.

Additional Feedback & John M. Eisenberg Awards Announcement

Led by Pat Mastors

The webinar concluded with a reminder that NQF is seeking applications before September 30th for its John M. Eisenberg Quality and Safety Award. The work of the Patient and Family Engagement Action team concludes in October, 2014.