THE PATIENT REVOLUTION PROJECT
An Initiative of the Knowledge and Evaluation Research Unit at Mayo Clinic
Supported by the Warburton Family

OVERVIEW

The Patient Revolution Project is built on a simple insight - that the best healthcare is that which incorporates a deep understanding of the patient’s life and goals. But yet, this kind of sharing happens less than it should, in part because patients have internalized the belief that stories from their lives which provide a window to their values and context are not welcome in the clinical setting. When patients don’t volunteer information from their life it is often because they fear being judged, or fear being a burden, or they don’t want to appear stupid for not understanding what the doctor is saying, or they perceive that their wishes may run counter to those of the clinical community.

We are attempting to reverse this trend through a program of activities and tools that give patients voice; encouraging proactive communication in clinical encounters and generally aiming to build patient skills and confidence in talking with their clinicians. The impact of this kind of empowered patient will be immediately evident in an individual’s interactions with their healthcare providers but it also promises the opportunity to transform healthcare delivery on a massive scale as the patterns of previously unacknowledged patients’ needs, values, goals and contexts become known.

HOW WE DO IT

We use human-centered design methods that incorporate observational research and interviews to understand the human issues at the root of a challenge and then employ an active experimentation and prototyping approach to develop interventions that address those needs. Once confidence is reached about a particular intervention, we examine its effect using clinical research methods.

ACHIEVEMENTS TO DATE

- Researched and produced an in-depth report on barriers to patient communication and participation
- Developed program tools (Reflection Document, Patient Stories Library, Social Shared Decision Making: Mammography, Plan Your Conversation Cards) and activities (Care Conversation Workshops) - Detailed in the following pages.
- Established partners to study tools and activities in a clinical setting. Experiments planned for August and September 2015 (Yale New Haven Hospital and Mayo Clinic)
- Outlined 1-year pilot proposal to bring the Patient Revolution Project program to partner communities and health systems
2015-2016 GOALS

- Continue to study and implement existing tools and activities
- Find community partners to collaborate in developing and running a year long pilot of our program - spreading existing tools and activities as well as developing additional ones.
- Formalize sustainability models and funding sources to allow for the expansion of the work

TEAM

The Knowledge and Evaluation Research (KER) Unit at Mayo Clinic focuses on discovery, translation and dissemination of health services research for patients and society.

Dr. Victor M. Montori, Professor of Medicine and researcher at Mayo Clinic has spent the last decade advancing patient-centered care and advocating for a patient revolution from the Knowledge and Evaluation Research Unit (KER UNIT). He serves as medical director and champion of the Patient Revolution Project.

Maggie Breslin (designer/researcher), Matt Maleska (designer/researcher) and Kim Savolainen (project manager) serve as co-directors of the Patient Revolution Project. They share a decade + of experience designing, developing and implementing innovative healthcare interventions to address the needs of patients and clinicians in the healthcare system.

The Warburton Family continues to advance the mission of Ralph T. Warburton, MD and Esther Lewis Warburton by joining with the KER Unit and Mayo Clinic in 2013 to further develop skill building programs and tools and expand the reach to people across the country.

CONTACT

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We conduct workshops for approximately 10-12 people in a makeshift exam room set to facilitate the discussion about patient-physician conversations.

We use the **Barrier Cards** during the first part of the workshop to have people reflect on their conversations with their doctors during previous clinical visits.

We use the **Plan Your Conversation** cards to have people identify and practice talking about an issue that they’d like to share with their doctor during their next visit. The cards ask them to finish the following phrases.

- **I want to talk about...**
- **It is important to me because...**
- **It might help you to know...**
- **I want this conversation to lead to...**
- **I am nervous this conversation will lead to...**

Many participants said that the structure of the **Plan the Conversation** cards allowed them to give voice to a topic that they hadn’t shared.

Many cards expressed nervousness that the conversations would end at solutions (an Rx, silly exercises) that didn’t fit into their lives.

People are constantly navigating having a new doctor and sharing their back story making good communication and storytelling skills important.
This initiative looks to collect stories of how the barriers to participation manifest in patients’ lives - capturing these stories allows for individuals who tell them to see the power of these barriers and allows those who see/hear the stories to connect with their own experiences.

Additionally these stories will likely have relevance for the clinical community as a window into the issues and challenges that are going undiscussed in current visits.

Sample stories revealed through this initiative include:

- A mother who was afraid to ask her daughter’s neurologist what the mother’s role in the child’s epilepsy might have been.
- A women who asked for clinical and genomic tests rather than reveal that the source of her anxiety about some of her health issues was the fact that she didn’t know her father.
- A man who was struggling with getting a vasectomy because of how his girlfriend might interpret the decision.
- A women with breast cancer who had to actively negotiate with her physicians because she wanted to choose a less intensive treatment protocol.
PLAN YOUR CONVERSATION CARDS

Ongoing

5 Cards asking patients to complete a statement as a strategy for identifying a topic they’d like to discuss with their clinicians.

This tool is used during the Care Conversation Workshop and could be used as a stand alone intervention. It has been suggested that they are valuable to give people upon dismissal from the hospital as a way of preparing for their next doctor’s visit.

I want to talk about...

It is important to me because...

It might help you to know...

I want this conversation to lead to...

I’m nervous this conversation will lead to...
A pre-clinic visit intervention designed to have patients reflect on dimensions of their lives and the relationship of those activities to their health. Initially being implemented in primary care setting.

TELL US ABOUT YOUR LIFE.

Please take a moment and try to answer the following 4 questions before your visit with the doctor. It may help you to think about your family and friends, your work, your neighborhood, your finances, your faith, your emotions, your sleep, your eating habits or what you do for fun while you answer these questions.

Tell us one NON-MEDICAL thing about your life that you think the doctor should know. (Where did you grow up? What do you do when you aren't at the clinic? What makes you famous?)

What is one thing your doctor is asking you to do for your health that feels like a burden or feels harder than it should?

What is one thing your doctor is asking you to do for your health that is helping you feel better?

Where do you find the most joy in your life?
WHAT IS BEST FOR ME AND MY FAMILY? DISCUSSION, MAMMOGRAPHY IN YOUR 40S
Ongoing | Rochester, MN and New Haven, CT

This initiative looks to bring shared decision making tools and the medical evidence contained within them outside the clinical environment into the community; creating forums for shared dialogue about topics ripe for patient engagement. Our first discussion topic is mammography screening for women in their 40s.

Out of 1000 Women during the course of 80 years...

- 113 will develop breast cancer. Some earlier in life, most later.
- 25 will die of breast cancer.
- 887 will not develop breast cancer.

In 1000 women who are not at increased risk of breast cancer during the years of age:

- 70-79: 31 will develop breast cancer, 8 will die of breast cancer, 960 will not develop breast cancer
- 60-69: 34 will develop breast cancer, 8 will die of breast cancer, 960 will not develop breast cancer
- 50-59: 28 will develop breast cancer, 8 will die of breast cancer, 972 will not develop breast cancer
- 40-49: 15 will develop breast cancer, 2 to 3 will die of breast cancer, 985 will not develop breast cancer
- 30-39: 4 will develop breast cancer, 2 to 3 will die of breast cancer, 996 will not develop breast cancer
- 20-29: fewer than 1 will develop breast cancer, fewer than 1 will die of breast cancer, more than 999 will not develop breast cancer

Out of 1000 Women during the course of the next 10 years...

- 34 will develop breast cancer during the years of age:
- 70-79
- 31 will develop breast cancer, 8 will die of breast cancer, 960 will not develop breast cancer
- 60-69
- 34 will develop breast cancer, 8 will die of breast cancer, 960 will not develop breast cancer
- 50-59
- 28 will develop breast cancer, 8 will die of breast cancer, 972 will not develop breast cancer
- 40-49
- 15 will develop breast cancer, 2 to 3 will die of breast cancer, 985 will not develop breast cancer
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- 4 will develop breast cancer, 2 to 3 will die of breast cancer, 996 will not develop breast cancer
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- fewer than 1 will develop breast cancer, fewer than 1 will die of breast cancer, more than 999 will not develop breast cancer


**WHAT HAPPENS NEXT**

Out of 1000 women like you over the course of the next 10 years that DO NOT get annual mammograms

- 14 will be diagnosed with breast cancer
- 986 will not be diagnosed with breast cancer
- 3 will die from breast cancer

Out of 1000 women like you over the course of the next 10 years that DO get annual mammograms

- 19 will be diagnosed with breast cancer
- 981 will not be diagnosed with breast cancer
- 6 will be diagnosed and receive unnecessary treatment for cancer that would have had no effect on their life
- 2 will die from breast cancer
- 631 will be called back for more imaging
- 70 will need a biopsy
- 19 will be diagnosed with breast cancer
- 369 will not be called back for more imaging

**BENEFIT OF SCREENING**

Out of 1000 women like you over the next 10 years that DO NOT get regular mammograms

- 14 will be diagnosed with breast cancer
- 986 will not be diagnosed with breast cancer
- 3 will die from breast cancer

Out of 1000 women like you over the next 10 years that DO get regular mammograms

- 19 will be diagnosed with breast cancer
- 981 will not be diagnosed with breast cancer
- 6 will be diagnosed and receive unnecessary treatment for cancer that would have had no effect on their life
- 2 will die from breast cancer

You may choose to have a mammogram at any time. You may be asked to consider having a mammogram when you turn 50.

**WHAT HAPPENS NEXT**

Out of 1000 women like you over the course of the next 10 years that DO get annual mammograms

- 14 will be diagnosed with breast cancer
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