



THE PATIENT REVOLUTION

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Minimally Disruptive Medicine Workshop | KER Unit
September 29, 2016

The Patient Revolution as the compliment to **MDM** and **SDM**.

SHARED CHALLENGES

- Generosity/empathy/compassion undervalued
- Relying on assumption

SHARED VISION

- Careful and kind care

WHAT DISTINGUISHES THE PATIENT REVOLUTION

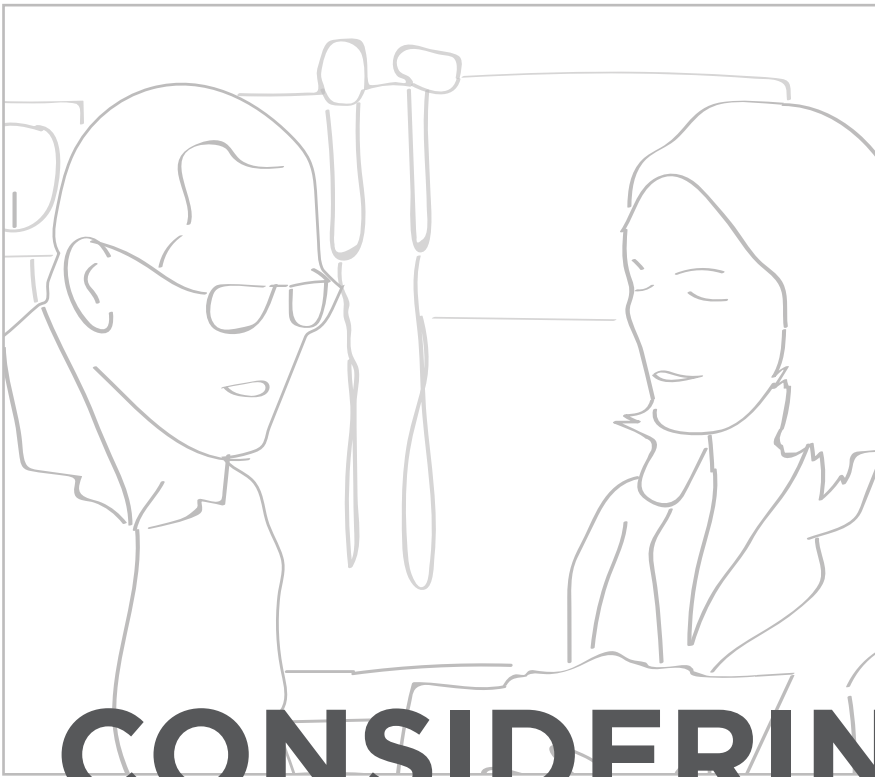
- the focus of our attention (WHO)
- scale of change we imagine (WHAT)
- moving from words to action (HOW)

WHAT WE ASK OF YOU

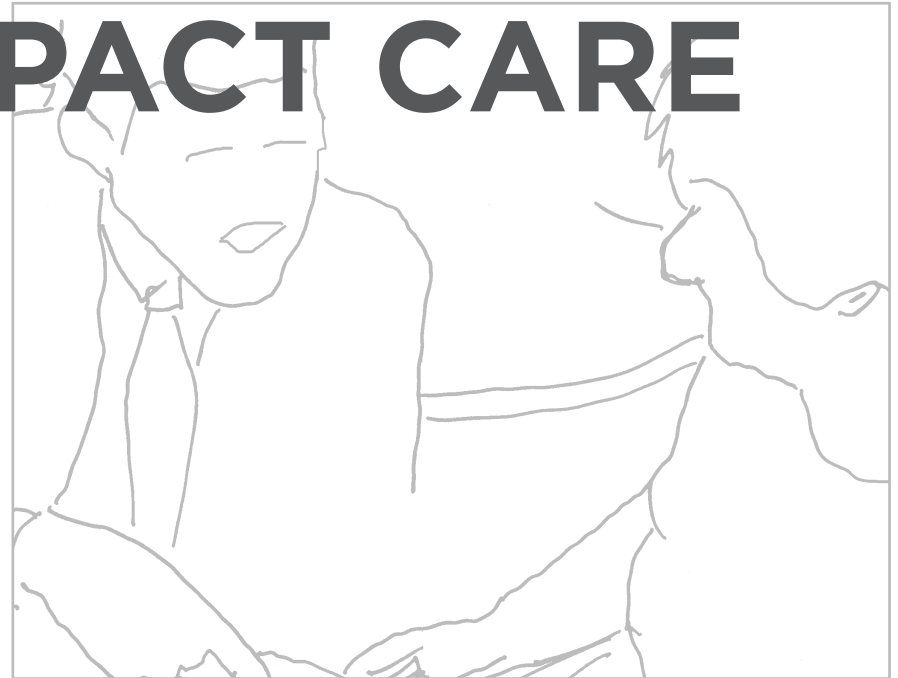
- advice
- critique
- perhaps, partnership and collaboration

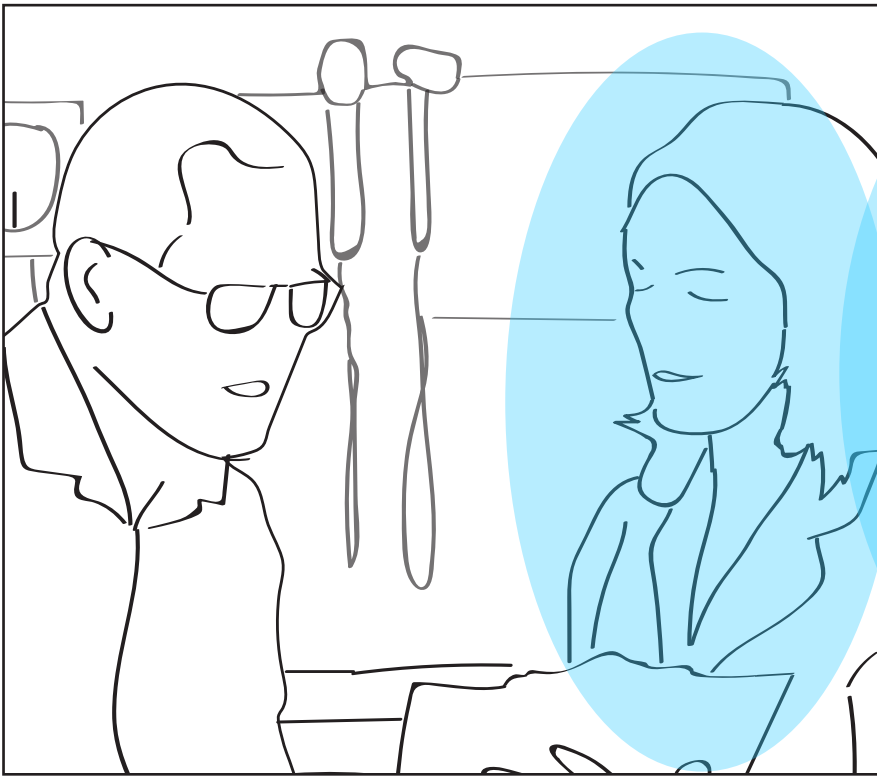


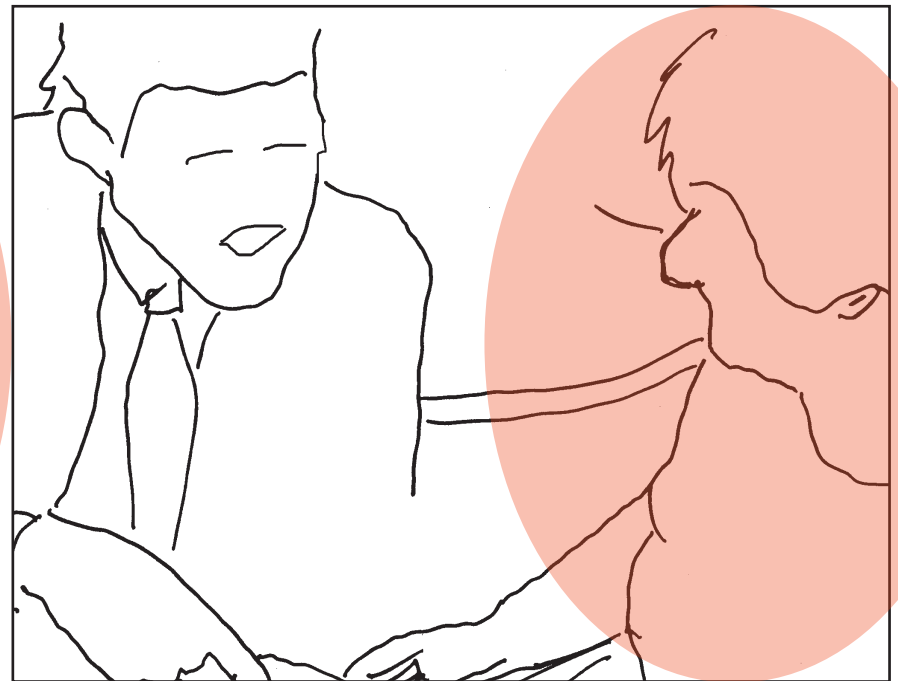
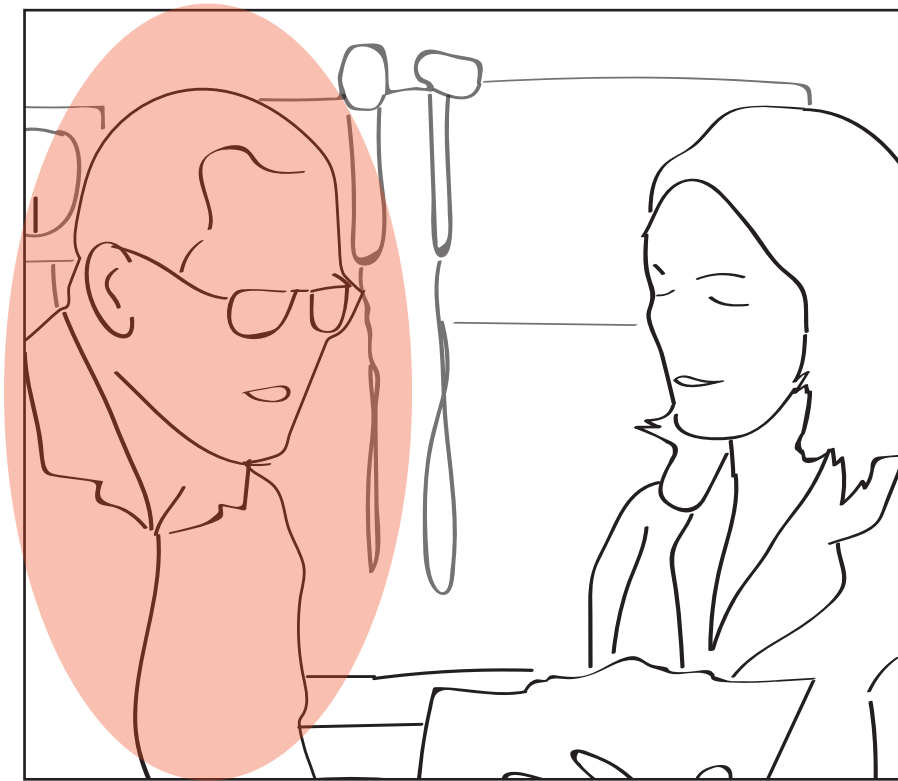
The focus of our attention—
**ON PATIENTS AND PUBLIC AS
VECTORS OF CHANGE**



CONSIDERING CARE AND HOW WE IMPACT CARE





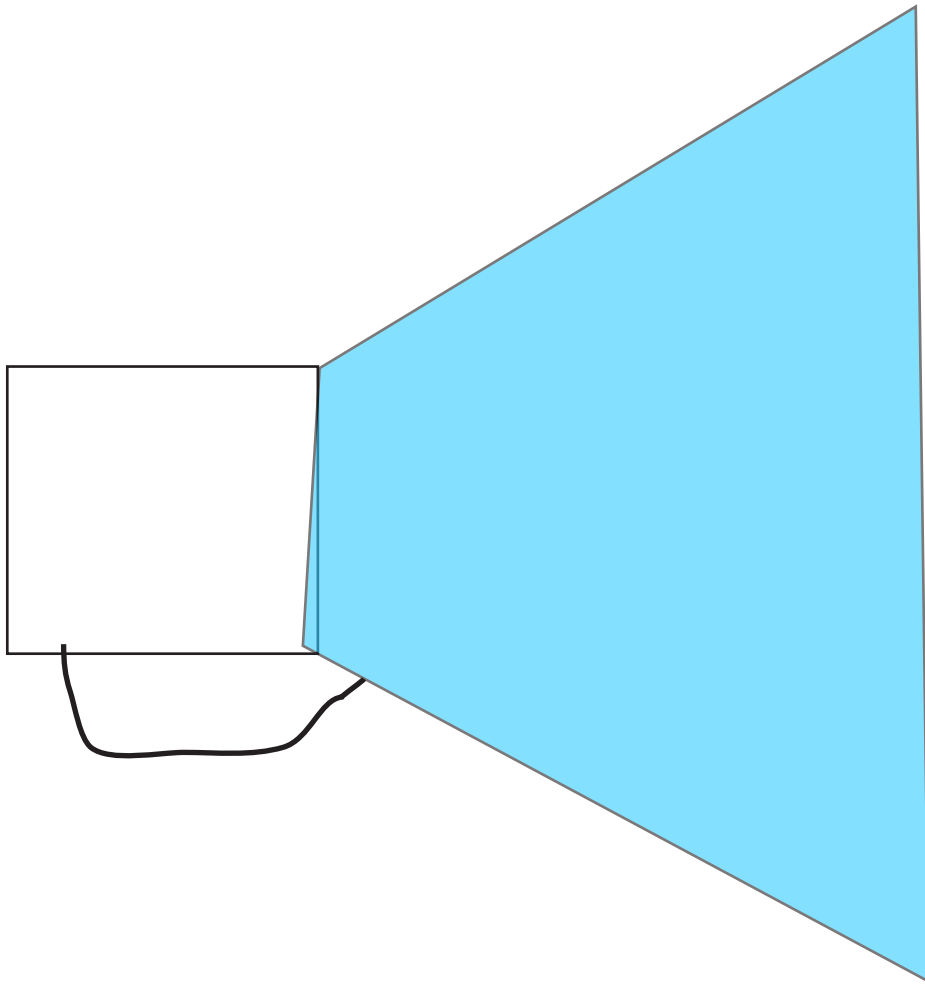




Scale of change we imagine possible—
**INDIVIDUAL, COMMUNITY,
NATIONAL, GLOBAL**

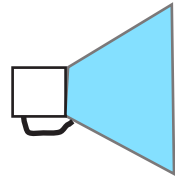
CHALLENGES TO GROWTH/SPREAD

- “a visit is only 10 minutes long”
- “you only get paid if you do x”
- requirement to hit quality measures
- guidelines interpreted as “must do”
- for that to happen, 10 things must change



Careful and Kind Care

Individuals

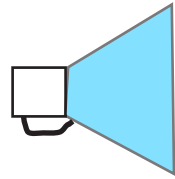


Clinicians

CHANGES TO

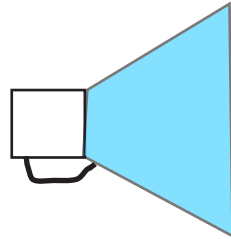
Care Plan

Individuals



Clinicians

Communities



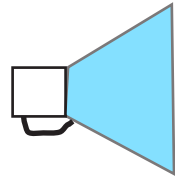
Clinical
Institutions

CHANGES TO

Care Plan

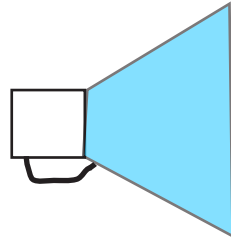
Community
programs, Clinical
systems and
priorities

Individuals



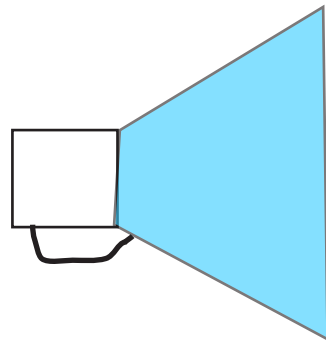
Clinicians

Communities



Clinical
Institutions

Public



Policymakers &
Organizations

CHANGES TO

Care Plan

Community
programs, Clinical
systems and
priorities

Inform debate,
Impact policies
and regulations

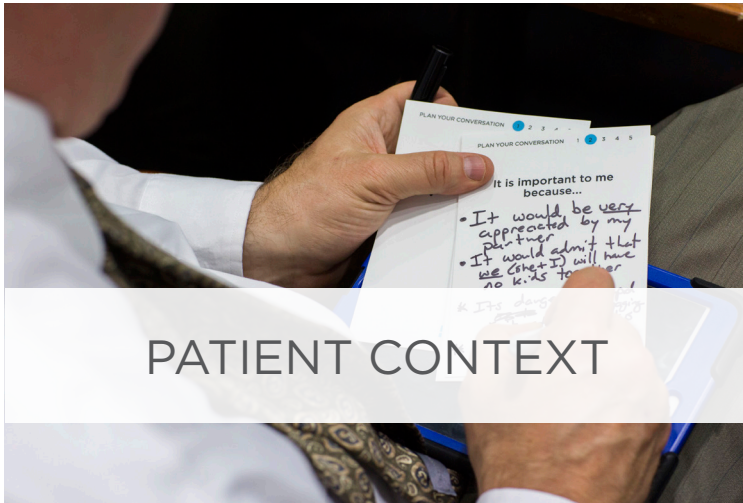


Moving from words to action–
**STORIES, TOOLS & SUPPORTED
COLLABORATION**

1. Support capturing, collating and visualizing stories and developing tools

2. Help ***PUSH*** those stories and tools into the clinical and public sphere

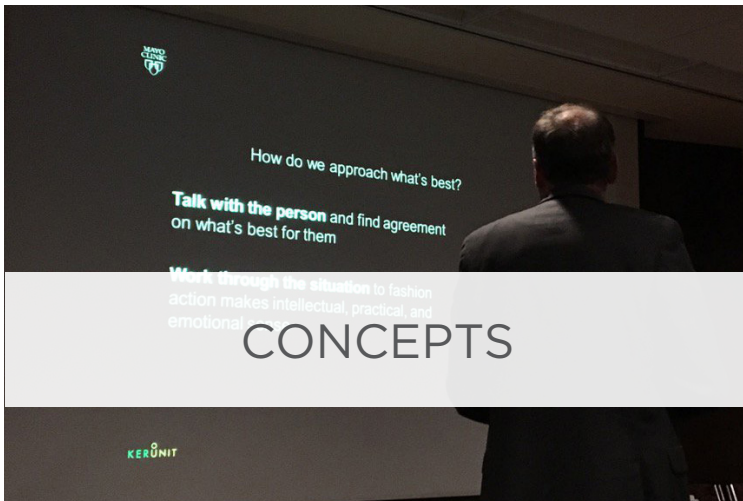
WHAT STORIES?



PATIENT CONTEXT



CLINICAL ENCOUNTERS



CONCEPTS



RESEARCH

WHAT TOOLS?



WHY STORIES?

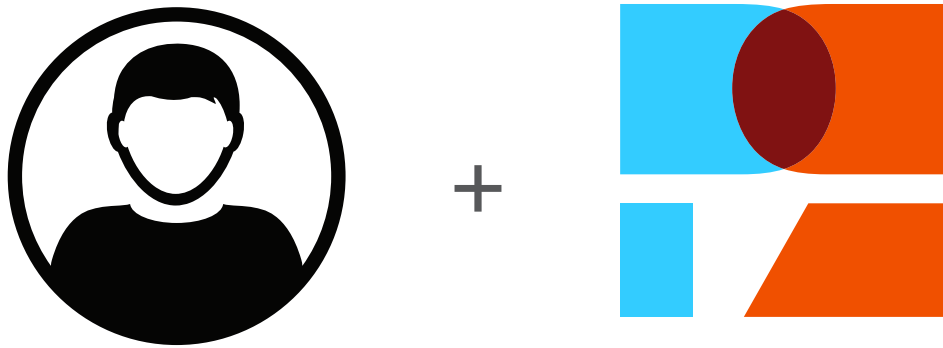
WHAT CAN STORIES & TOOLS DO?

- inform
- inspire
- irritate
- sustain

SUPPORTED COLLABORATION



SUPPORTED COLLABORATION





So far...

TOOLS & PROGRAMS

RESEARCH INTO BARRIERS

- . I don't want my comment or question to make me appear unintelligent or concerned about the wrong things.
- . I don't want to be a burden to my doctor.
- . I assume that the doctor's recommendation is the only option or the best option.
- . I don't want my doctor to think of me as a difficult patient.
- . I assume that if an aspect of my life is important, the doctor will ask me about it.
- . I assume that decisions need to be made right away.
- . I worry I'll be judged for considering cost in making decisions about my health.
- . I'm afraid of being judged if my choices are different from what most other people would do.

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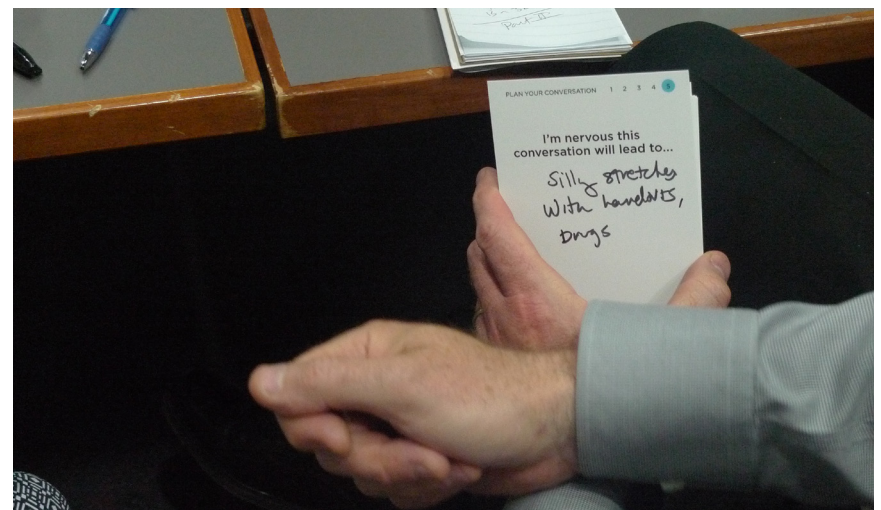
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CARE CONVERSATION WORKSHOP

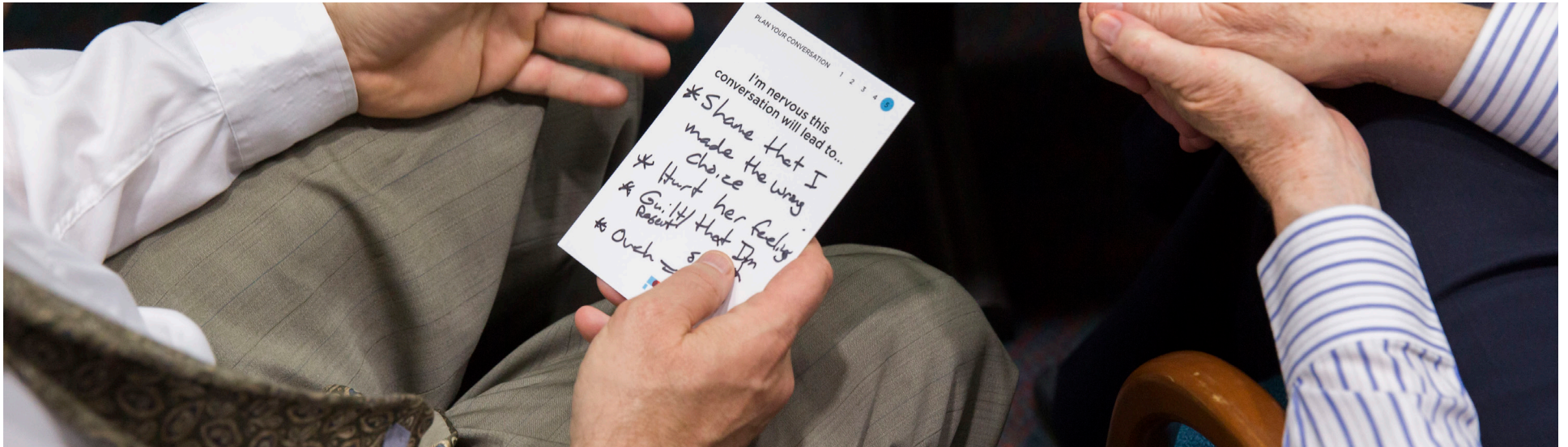


"Talking to strangers about how you feel in a doctor's office is a strangely bonding experience, as it turns out. "

- Paul Scott, Rochester Post-Bulletin



PLAN YOUR CONVERSATION & PRACTICE SESSION



PLAN YOUR
CONVERSATION
1

I want to talk about...



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PLAN YOUR
CONVERSATION
2

It is important to me because...



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CONVERSATION
3

It might help you to know...



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CONVERSATION
4

I want this conversation
to lead to...



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CONVERSATION
5

I'm nervous this conversation
will lead to...



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REFLECTION DOCUMENT

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 is helping you feel better?

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?

Where do you find the most joy in your life?

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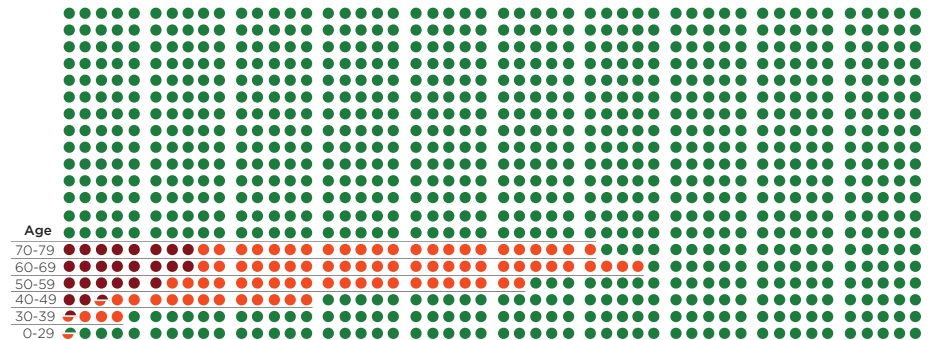
Where do you find the most joy in your life?

SOCIAL SHARED DECISION MAKING MODEL



WHAT IS BEST FOR ME AND MY FAMILY? A DISCUSSION OF MAMMOGRAPHY SCREENING IN YOUR 40S

Out of 1000 women over the course of the next 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	969 will not develop breast cancer
60-69	34 will develop breast cancer	8 will die of breast cancer	966 will not develop breast cancer
50-59	28 will develop breast cancer	6 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	fewer than 1 will die of breast cancer	996 will not develop breast cancer
0-29	fewer than 1 will develop breast cancer	fewer than 1 will die of breast cancer	more than 999 will not develop breast cancer

Source: AIHW & Australian Association of Cancer Registries (2004). Cancer in Australia 2001. AIHW (Cancer Series No. 28) cited in <http://canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/your-risk/calculate>

THE PATIENT REVOLUTION
A program of the Knowledge and Evaluation Research Unit at Mayo Clinic.

SOCIAL SHARED DECISION MAKING MODEL - OTHER TOPICS

- set your A1C target
- discuss cardiovascular risk
- colon cancer screening
- other preventative screening



Where we are...

MISSION STATEMENT *(in progress)*

The Patient Revolution is an **action and advocacy movement for careful and kind patient care** that supports patients and the public in pushing stories into the clinical and public sphere that remind us of the importance and possibility of empathy, compassion and generosity in health care.

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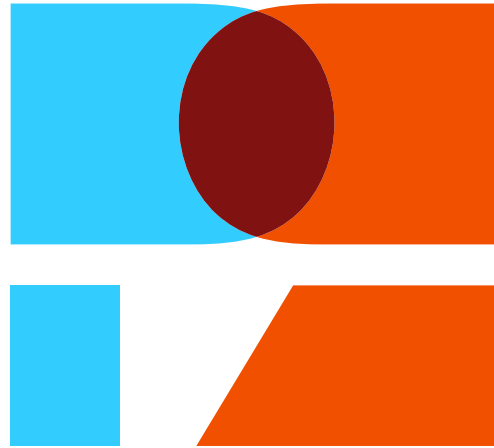
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(It is also its own 501c3 non-profit now)

REACHING COMMUNITIES & INDIVIDUALS

- Making tools and support available digitally through our website
- Exploring strategies to connect and reach more people
- Communities to collaborate

If you have people you think we should meet, stories you think we should tell, reach out.



THANK YOU.

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