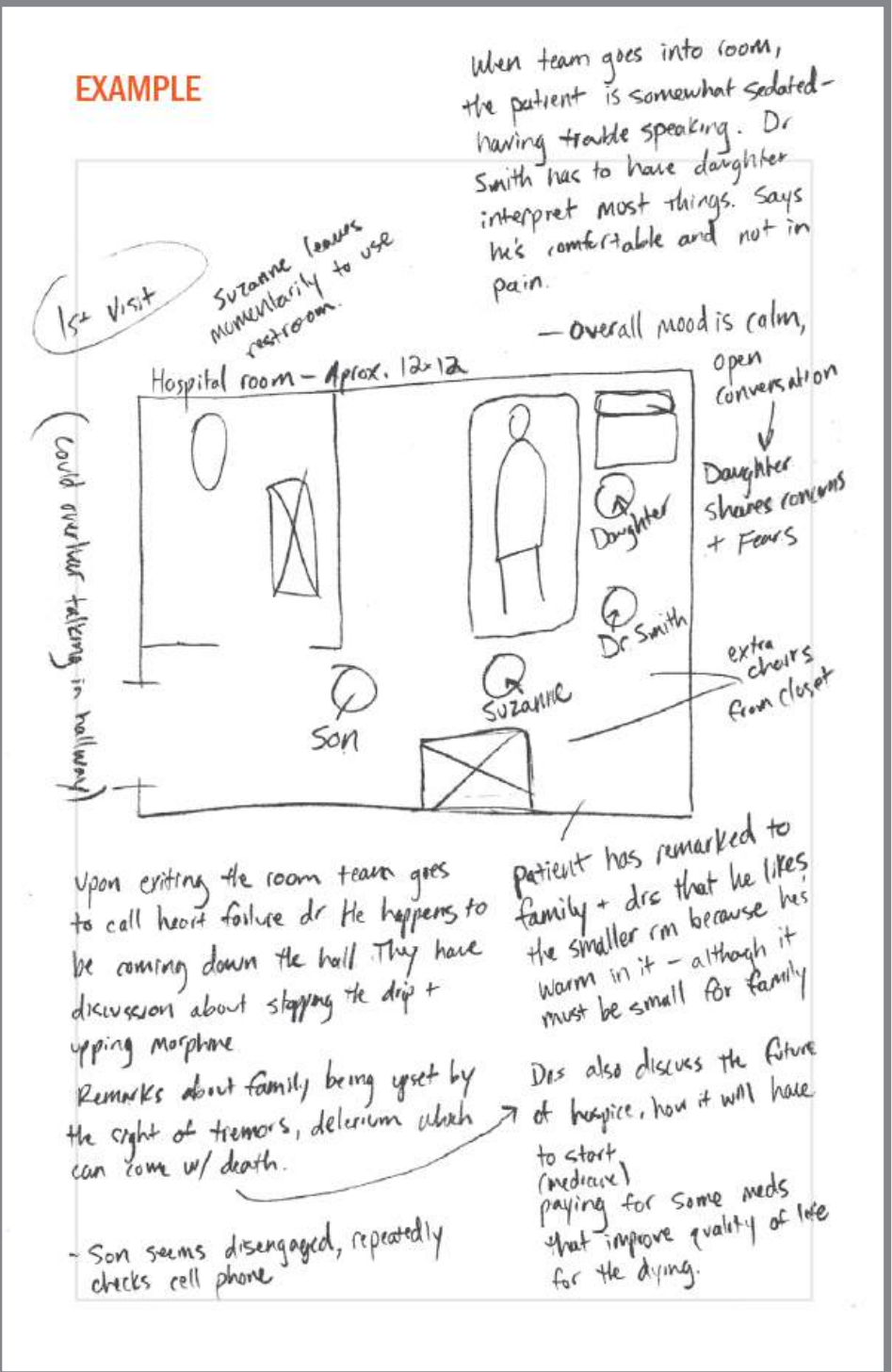


# Designing for Conversations Shared Decision Making in Practice

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# Designer & Researcher



# COLLABORATORS

some partners in development and research



Yale School of Medicine  
Endocrinology



# Diabetes Issue Cards: A short case study (2005)



most decision making in practice



hypothesis



# Prototype 1: baseball cards

Metformin

FORM

Pill

USED WITH

Alone or with Sulfonylureas

EFFECTIVENESS

able to lower A1c by 1–2%

WHEN TAKEN

twice (2) daily  
*with meals ideally but not absolutely necessary*

WEIGHT SIDE EFFECTS

minimal to no weight gain

OTHER SIDE EFFECTS

some nausea, dyspepsia and diarrhea possible in the first two (2) weeks. Then most people can get used to it.

SEVERE HYPOGLYCEMIA

0 in 100 (within year of use)

MINOR HYPOGLYCEMIA

1–2 in 100 (within year of use)

MONITORING NEEDS

none when used alone

+ Sulfonylureas

2–5 times/week initially

+ Insulin

daily

Exenatide

FORM

Injectable medication

USED WITH

Metformin or Sulfonylureas

EFFECTIVENESS

able to lower A1c by 0.5–1%

WHEN TAKEN

twice (2) daily  
*in the 1 hour before breakfast and dinner*

WEIGHT SIDE EFFECTS

+ Metformin  
loss of 1.5–3kg (3–6 lbs) after 6–7 months

+ Metformin and Sulfonylureas  
loss of about 1.5kg (3 lbs)

OTHER SIDE EFFECTS

initial nausea; about 40 in 100  
persistent nausea; about 15 in 100  
severe nausea; 3 in 100  
diarrhea; 12–16 in 100

SEVERE HYPOGLYCEMIA

+ Metformin  
none

+ Metformin and Sulfonylureas  
1 in 400

MINOR HYPOGLYCEMIA

+ Metformin  
5 in 100

+ Metformin and Sulfonylureas  
30 in 100 (within 30 weeks of use)

MONITORING NEEDS

+ Metformin  
initially 2–5 times/week, less when stable  
occasionally 2–3 hours after eating

+ Metformin and Sulfonylureas  
initially daily and after eating, then 2–5 times/week or less when stable

Metformin

FORM

Pill

USED WITH

Alone or with Sulfonylureas

EFFECTIVENESS

able to lower A1c by 1–2%

WHEN TAKEN

twice (2) daily  
*with meals ideally but not absolutely necessary*

WEIGHT SIDE EFFECTS

minimal to no weight gain

OTHER SIDE EFFECTS

some nausea, dyspepsia and diarrhea possible in the first two (2) weeks. Then most people can get used to it.

SEVERE HYPOGLYCEMIA

0 in 100 (within year of use)

MINOR HYPOGLYCEMIA

1–2 in 100 (within year of use)

MONITORING NEEDS

none when used alone

+ Sulfonylureas

2–5 times/week initially

+ Insulin

daily

Sulfonylureas

*glimepiride or Amaryl; glipizide or Glucotrol*

FORM

Injectable medication

USED WITH

Alone or with Metformin and/or Sulfonylureas

EFFECTIVENESS

able to lower A1c by 1–2%

WHEN TAKEN

twice (2) daily  
*used twice a day  
30 minutes before breakfast (meal)*

WEIGHT SIDE EFFECTS

gain of 2–3kg (4–6lbs)

OTHER SIDE EFFECTS

nausea; about 1–2 in 100  
diarrhea; about 1–2 in 100  
rash; about 1–2 in 100

SEVERE HYPOGLYCEMIA

8 in 1000 (within year of use)

MINOR HYPOGLYCEMIA

21 in 100 (within year of use)

MONITORING NEEDS

initially 2–5 times/week, less when stable

Insulin

FORM

Injectable medication

USED WITH

Alone or with Metformin and/or Sulfonylureas

EFFECTIVENESS

no limit to A1c reduction

WHEN TAKEN

once (1) or twice (2) daily

WEIGHT SIDE EFFECTS

gain of about 4kg (8–9lbs)

SEVERE HYPOGLYCEMIA

1–3 in 100 (within year of use)

MINOR HYPOGLYCEMIA

30–40 in 100 (within year of use)

MONITORING NEEDS

daily; once (1) or twice (2)/day



# Prototype 2: narrative cards

## Exenatide (Byetta)

<b>FORM</b> Injectable medication	<b>WHEN TAKEN</b> Twice (2) daily; in the morning and evening before eating
<b>TYPICALLY USED WITH</b> Metformin or Sulfonylureas	<b>MONITORING</b> If taking Sulfonylureas, monitor daily after meals. Once stable, you can monitor less often.

**EFFECTIVENESS**  
Exenatide typically lowers A1c by 0.5–1%.

**WEIGHT EFFECTS**  
Exenatide has been shown to promote weight loss, an area of concern among many people with diabetes. If you are currently taking Metformin, you may lose 3 to 6 pounds after 6–7 months of taking Exenatide. If you are taking Metformin and Sulfonylureas, the weight loss will be less because Sulfonylureas have the side effect of weight gain. Still, you may experience a loss of about 3 pounds on Exenatide.

**HYPOGLYCEMIA**  
When used with Metformin, there is no risk of severe hypoglycemia and the chance of minor hypoglycemia is about 5 in 100. When used with Metformin and Sulfonylureas, the risk of severe hypoglycemia is less than 1 in 100 and for minor hypoglycemia 30 in 100 (within 30 weeks).

**OTHER SIDE EFFECTS**  
Other side effects of Exenatide may include nausea and diarrhea. Of 100 people like you, 40 will experience initial nausea with 15 of those experiencing persistent nausea and 3 experiencing severe nausea. Between 12–16 of 100 people will have some form of diarrhea.

## Glitazones (pioglitazone or Actos; rosiglitazone or Avandia)

<b>FORM</b> Pill	<b>WHEN TAKEN</b> Once (1) daily
<b>TYPICALLY USED WITH</b> Alone or with Metformin and/or Sulfonylureas	<b>MONITORING</b> Occasionally with Metformin; 3–5 times per week with Sulfonylureas. Once stable, you can monitor less often.

**EFFECTIVENESS**  
With Metformin, Glitazones typically lower A1c by 1%. With Metformin and Sulfonylureas, Glitazones may be able to lower A1c by 1–2%.

**WEIGHT EFFECTS**  
A common effect of Glitazones is weight gain. When paired with Metformin, which does not typically have a weight gain effect, the average weight gain is 2–6 pounds. When combined with Sulfonylureas, which do have a weight gain effect, the combined average weight gain can be between 2–13 pounds.

**HYPOGLYCEMIA**  
Glitazones cause no risk of severe hypoglycemia. The risk of minor hypoglycemia shows 2 of 100 people like yourself experiencing some symptoms within one year of use.

**OTHER SIDE EFFECTS**  
The primary side effect of Glitazones is edema, fluid retention. Approximately 10 out of every 100 people like you may experience some swelling of the ankles. If you have heart failure, fluid retention may affect your breathing.

## Insulin

<b>FORM</b> Injectable medication	<b>WHEN TAKEN</b> Once (1) or twice (2) daily
<b>TYPICALLY USED WITH</b> Alone or with Metformin and/or Sulfonylureas	<b>MONITORING</b> Initially once (1) or twice (2) per day. Once stable, you can monitor less often.

**EFFECTIVENESS**  
There is no limit to the amount of A1c reduction you can receive with Insulin.

**WEIGHT EFFECTS**  
Insulin is often associated with weight gain. On average, most people who use Insulin will see a weight gain of around 8–9 pounds.

**HYPOGLYCEMIA**  
Of 100 people like yourself who use insulin, between 1 and 3 will experience severe hypoglycemia within a year of use. The risk of minor hypoglycemia is greater with between 30 and 40 people out of every 100 exhibiting some symptoms within a year of use.

**OTHER SIDE EFFECTS**  
There are no other significant side effects associated with Insulin.

## Metformin (Glucophage)

**FORM**  
Pill

**TYPICALLY USED WITH**  
Alone or with Sulfonylureas

**WHEN TAKEN**  
Twice (2) daily; with meals ideally

**MONITORING**  
Initially 2–5 times per week. Once stable, you can monitor less often.

**EFFECTIVENESS**  
Metformin has shown an ability to lower your A1c by 1–2%.

**WEIGHT EFFECTS**  
Metformin use has not been associated with significant changes in weight so you can expect minimal to no weight gain.

**HYPOGLYCEMIA**  
Metformin causes no risk of severe hypoglycemia. The risk of minor hypoglycemia shows 1–2 people out of 100 like yourself experiencing some symptoms within one year of use.

**OTHER SIDE EFFECTS**  
When you first begin taking Metformin, you may experience some nausea, dyspepsia or diarrhea in the first two (2) weeks. After that, most people become accustomed to the drug.

## Sulfonylureas (glimeperide or Amaryl; glipizide or Glucotrol)

<b>FORM</b> Pill	<b>WHEN TAKEN</b> Once (1) or twice (2) daily, 30 minutes before a meal
<b>TYPICALLY USED WITH</b> Alone or with Metformin	<b>MONITORING</b> Initially 2–5 times per week. Once stable, you can monitor less often.

**EFFECTIVENESS**  
Sulfonylureas typically lower A1c by 1–2%.

**WEIGHT EFFECTS**  
A common effect of Sulfonylureas is weight gain. The average gain is between 4–6 pounds although it should be noted that some people don't gain any weight at all and others may gain more than the average.

**HYPOGLYCEMIA**  
The risk of severe hypoglycemia with Sulfonylureas is less than 1 in 100 within a year of use. Within the same time frame (a year), the likelihood of experiencing minor hypoglycemia is 21 out of 100.

**OTHER SIDE EFFECTS**  
Other side effects of Sulfonylureas include nausea, rash and diarrhea. In studies of people like you, the likelihood of experiencing nausea, rash or diarrhea is about 1–2 in 100.



# Prototype 3: decision board









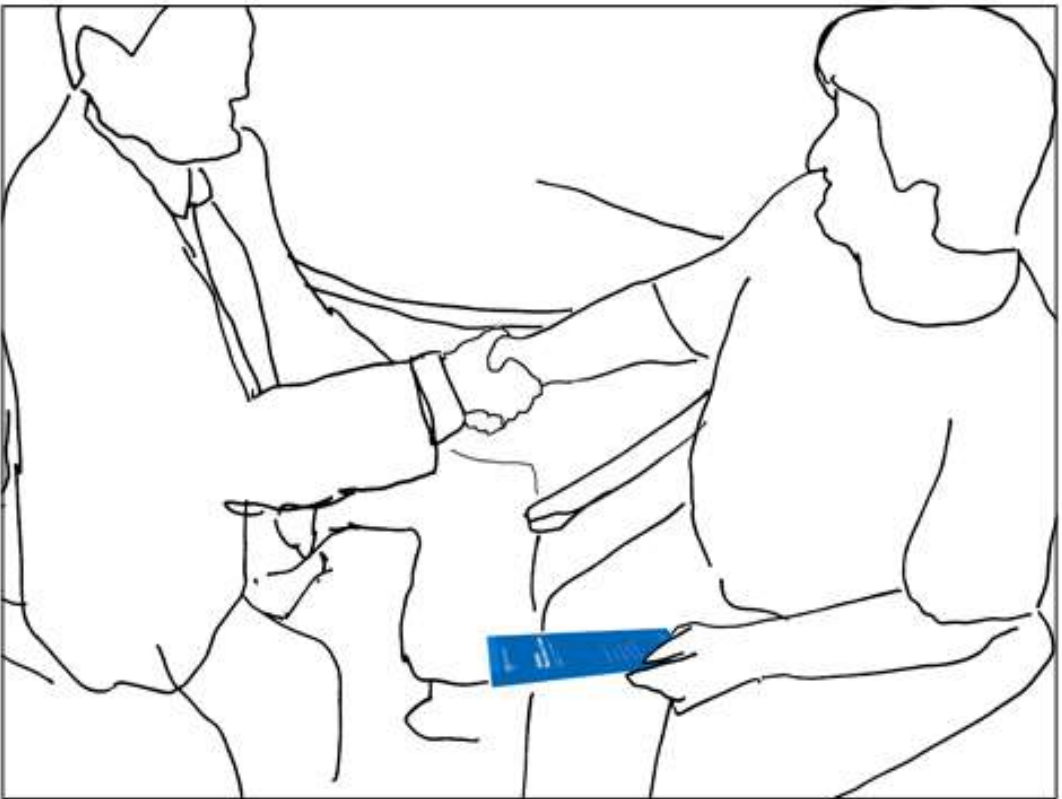
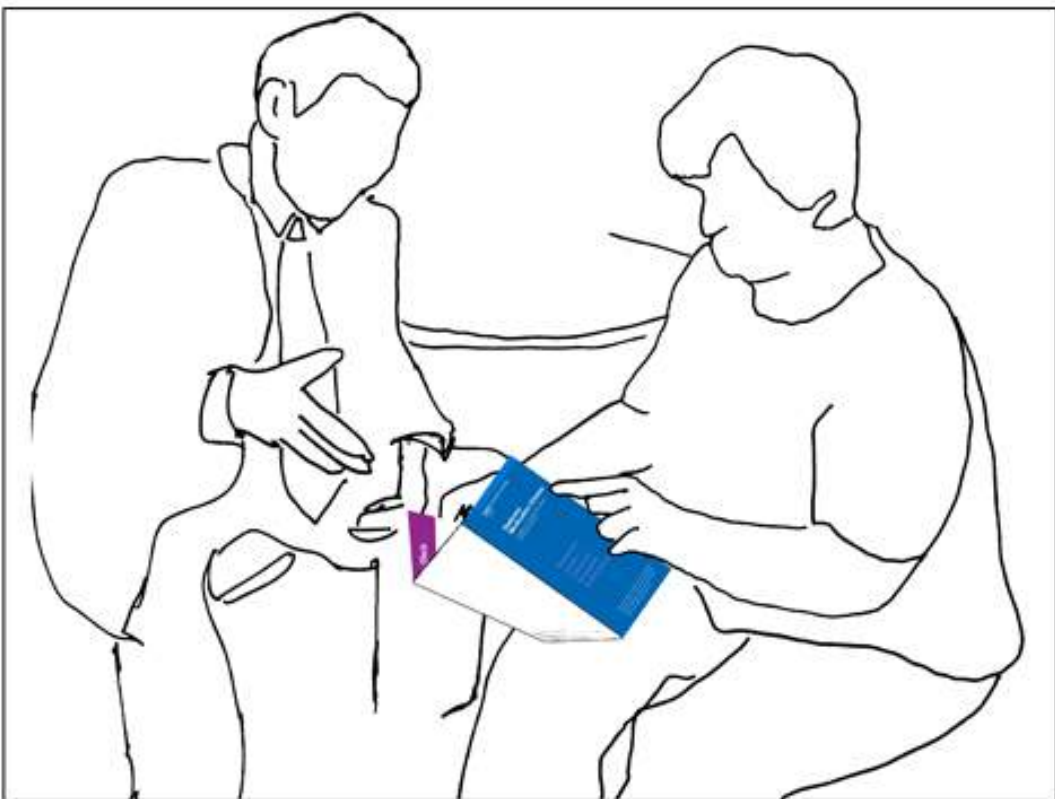
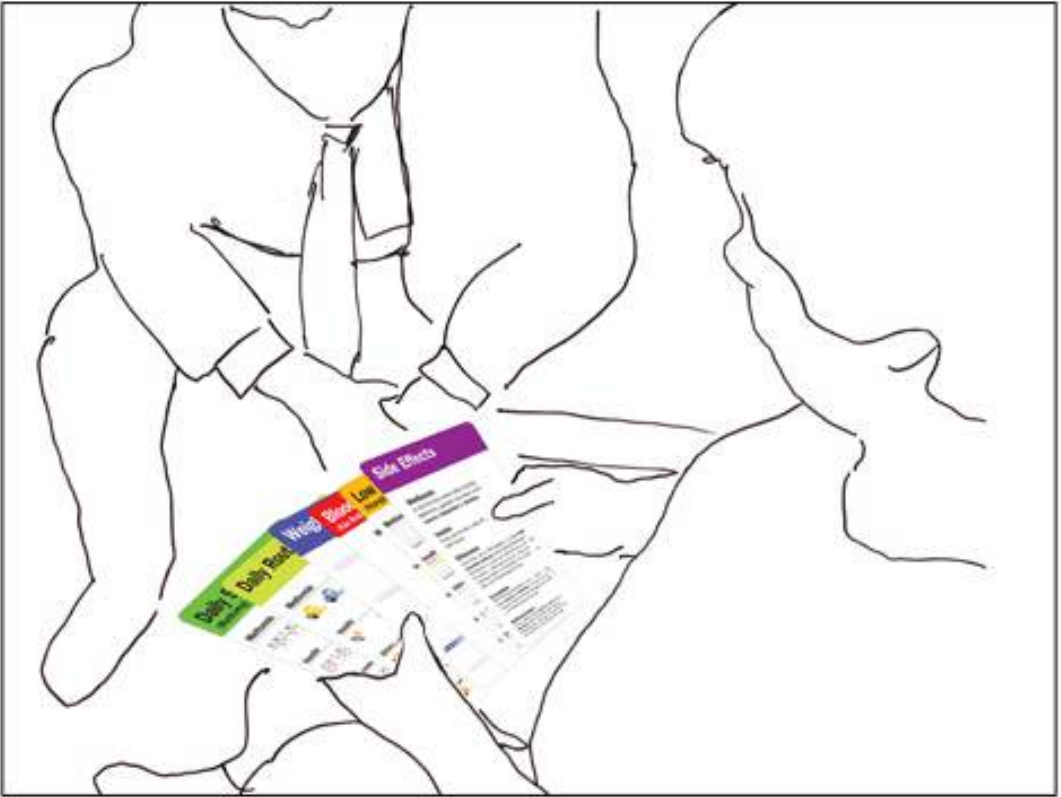
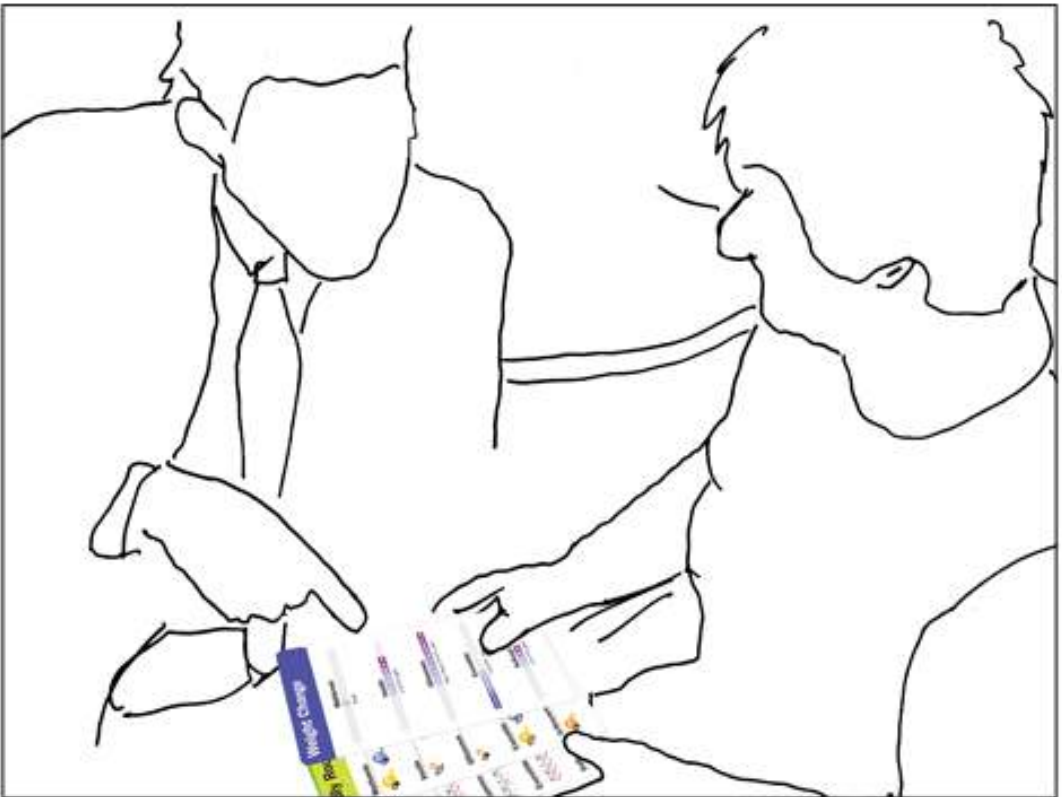
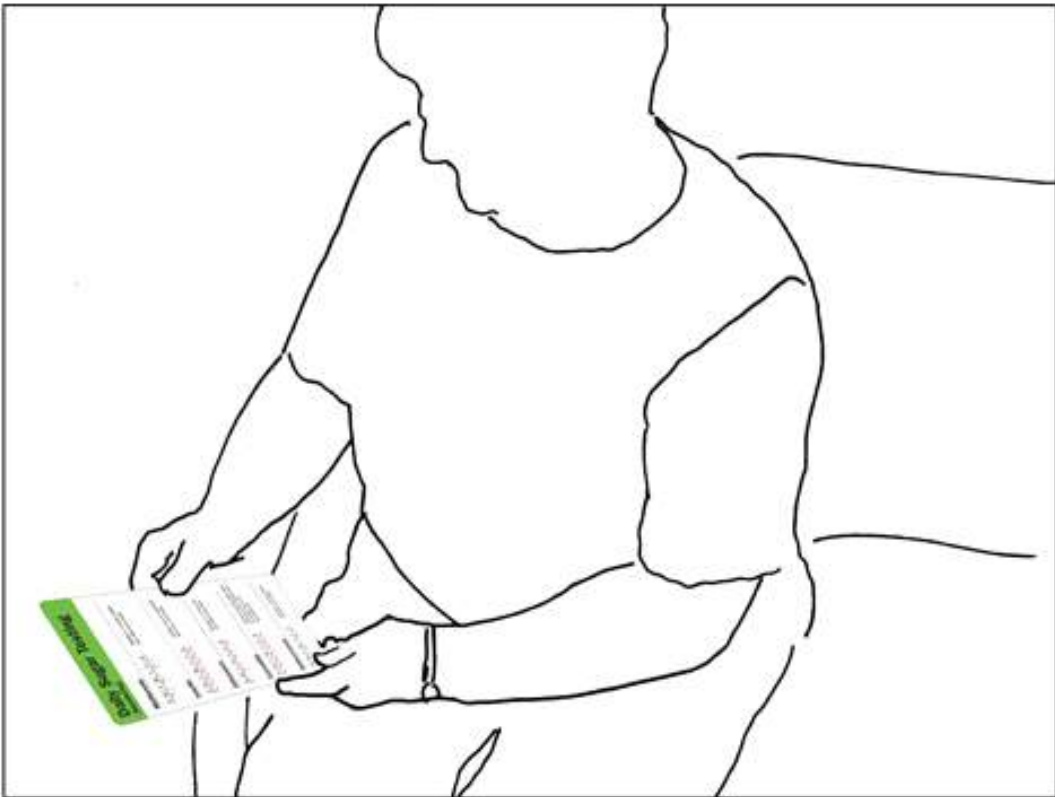
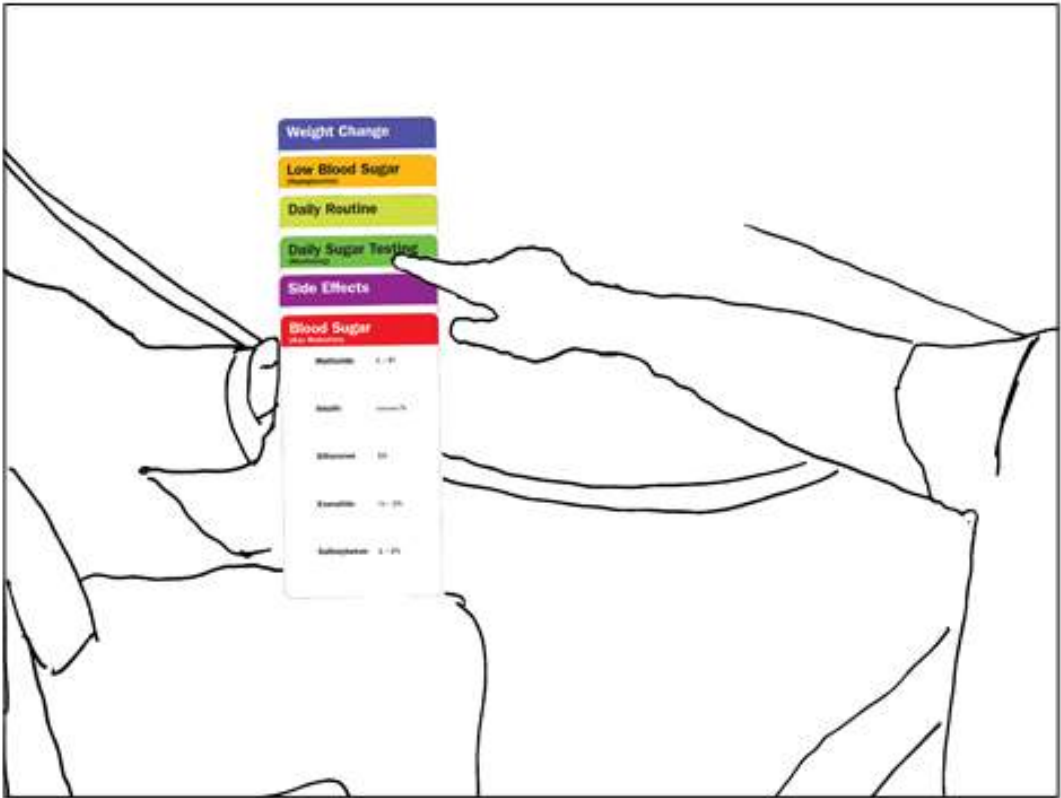
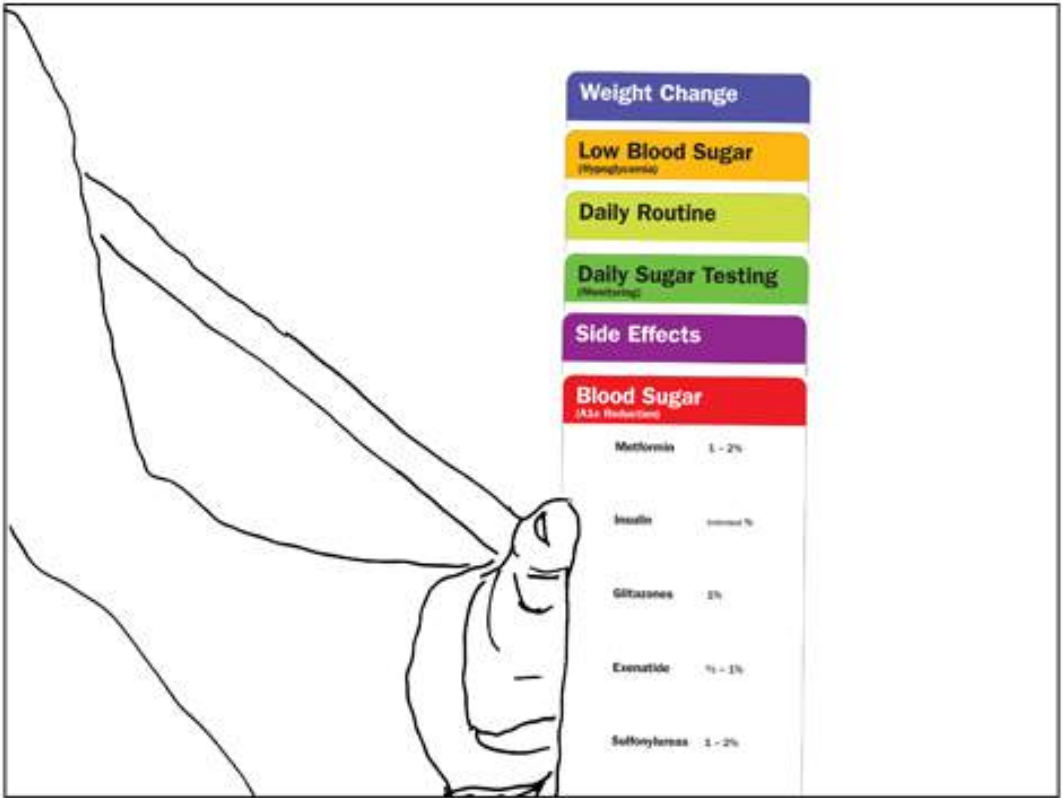
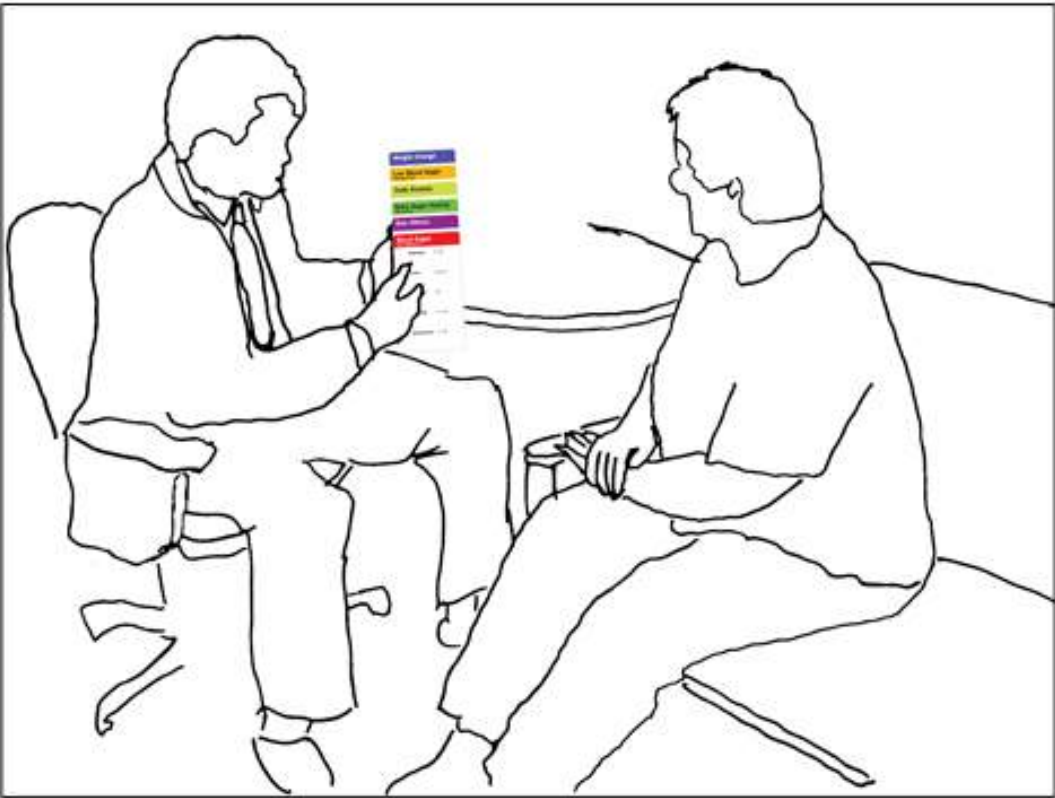
# Learnings and Advice

- Care happens in conversation
- Success is a care plan for this patient ≠ patients like this
- Evaluate tools by gathering stories + measurable data
- Good interventions aim to create the conditions for care



Care happens in conversation.









## NOTICE

Looking at &  
engaging

Recognizing each  
other as people

Looking for  
strengths





## RESPOND

Creating a  
productive plan

Drawing from  
best-available  
knowledge and  
research

Commitment to  
work together

Showing  
compassion





## SETTING

Enough time

Necessary  
resources

Few disruptions



Success is a **care plan** for  
**this patient** ≠ patients like this







# HbA1c < 7%

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## 4 Statin Benefit Groups

- Clinical ASCVD\*
  - LDL-C  $\geq 190$  mg/dL, Age  $\geq 21$  years
  - Primary prevention-Diabetes: age 40-75 years, LDL-C 70-189 mg/dL
  - Primary prevention - no diabetes  $\geq 7.5\%$  10 year
- 





Maria Luisa ≠ People like Maria Luisa





Evaluate tools by gathering **stories** +  
measurable data.



### ACCURATE KNOWLEDGE



50%

### RECEIVED INFORMATION

Right amount



69%

Very clear



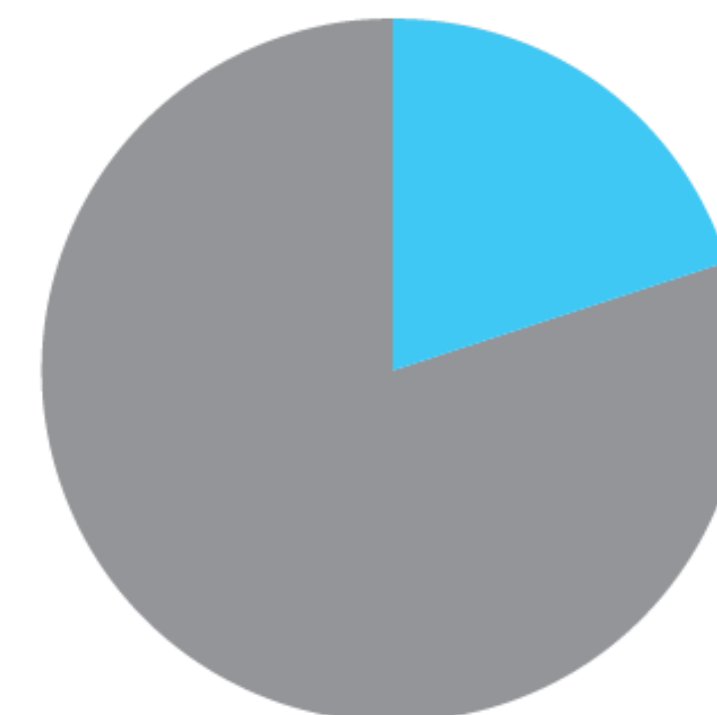
30%

Very helpful



27%

### ENGAGEMENT OF PATIENTS



19%

### ESTIMATED RISK CORRECTLY

12%

### WANT TO RECEIVE INFORMATION IN THE SAME MANNER

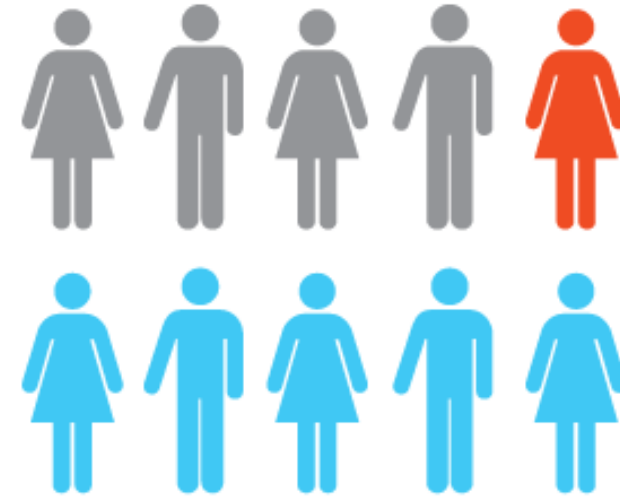
42%



Usual Care

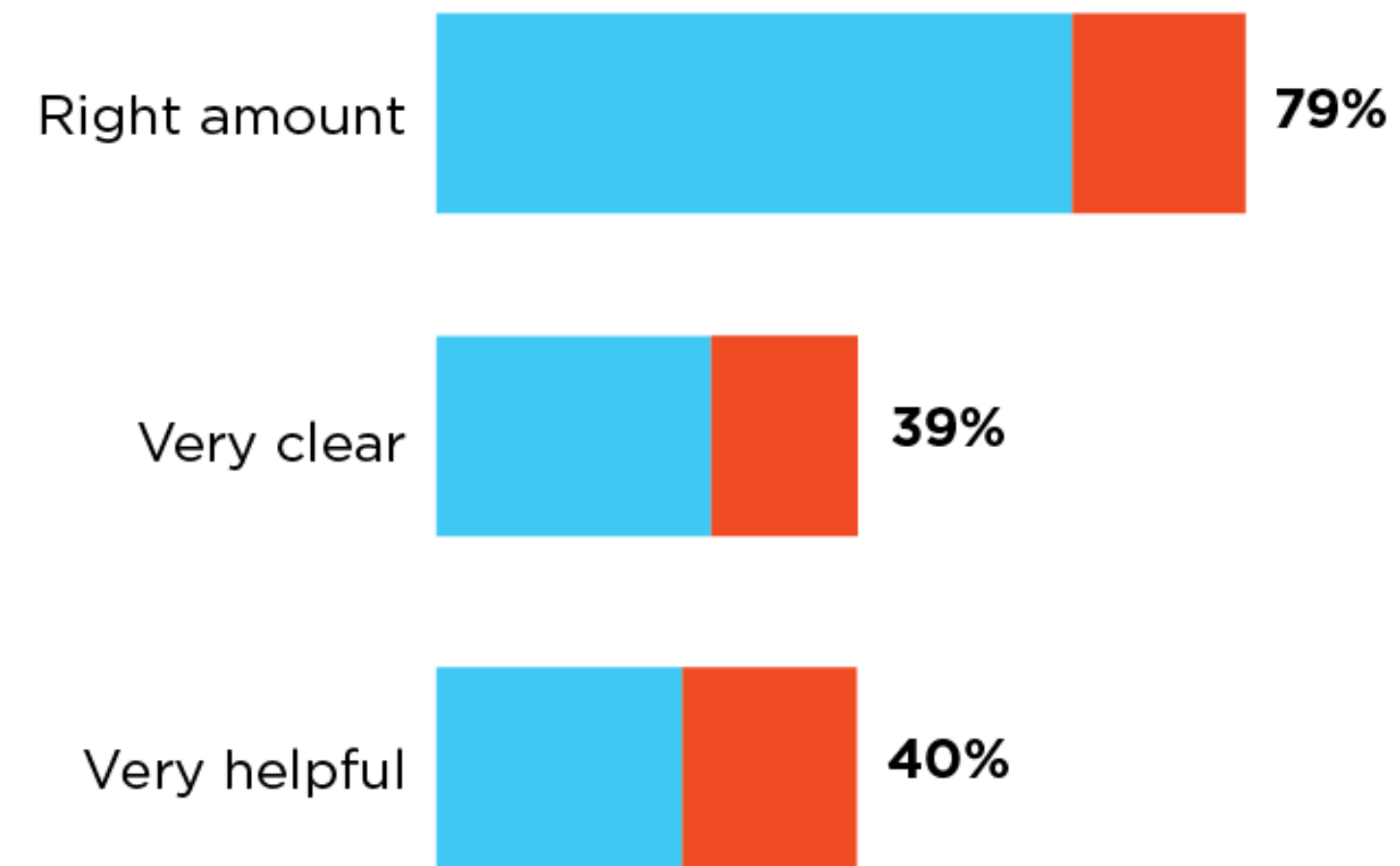


### ACCURATE KNOWLEDGE

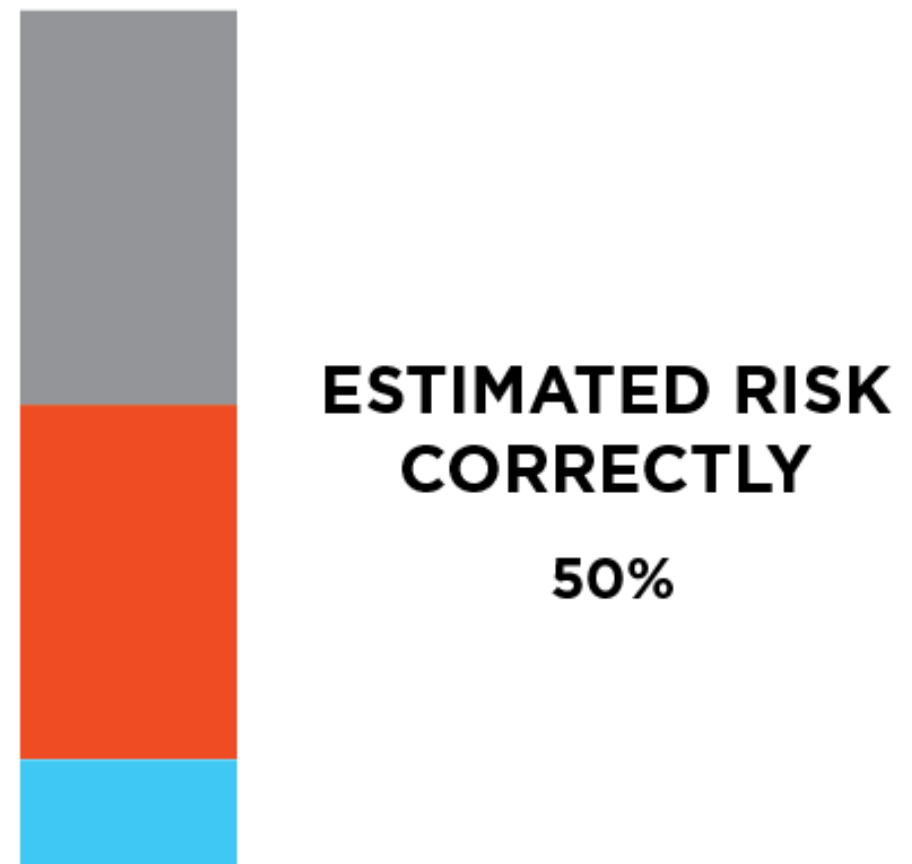
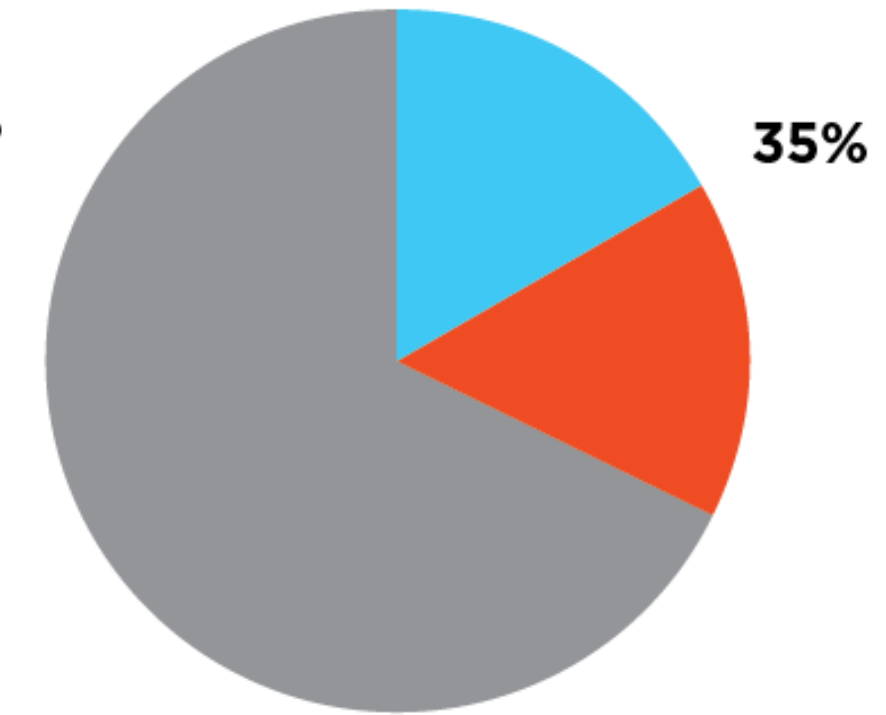


60%

### RECEIVED INFORMATION



### ENGAGEMENT OF PATIENTS



### WANT TO RECEIVE INFORMATION IN THE SAME MANNER



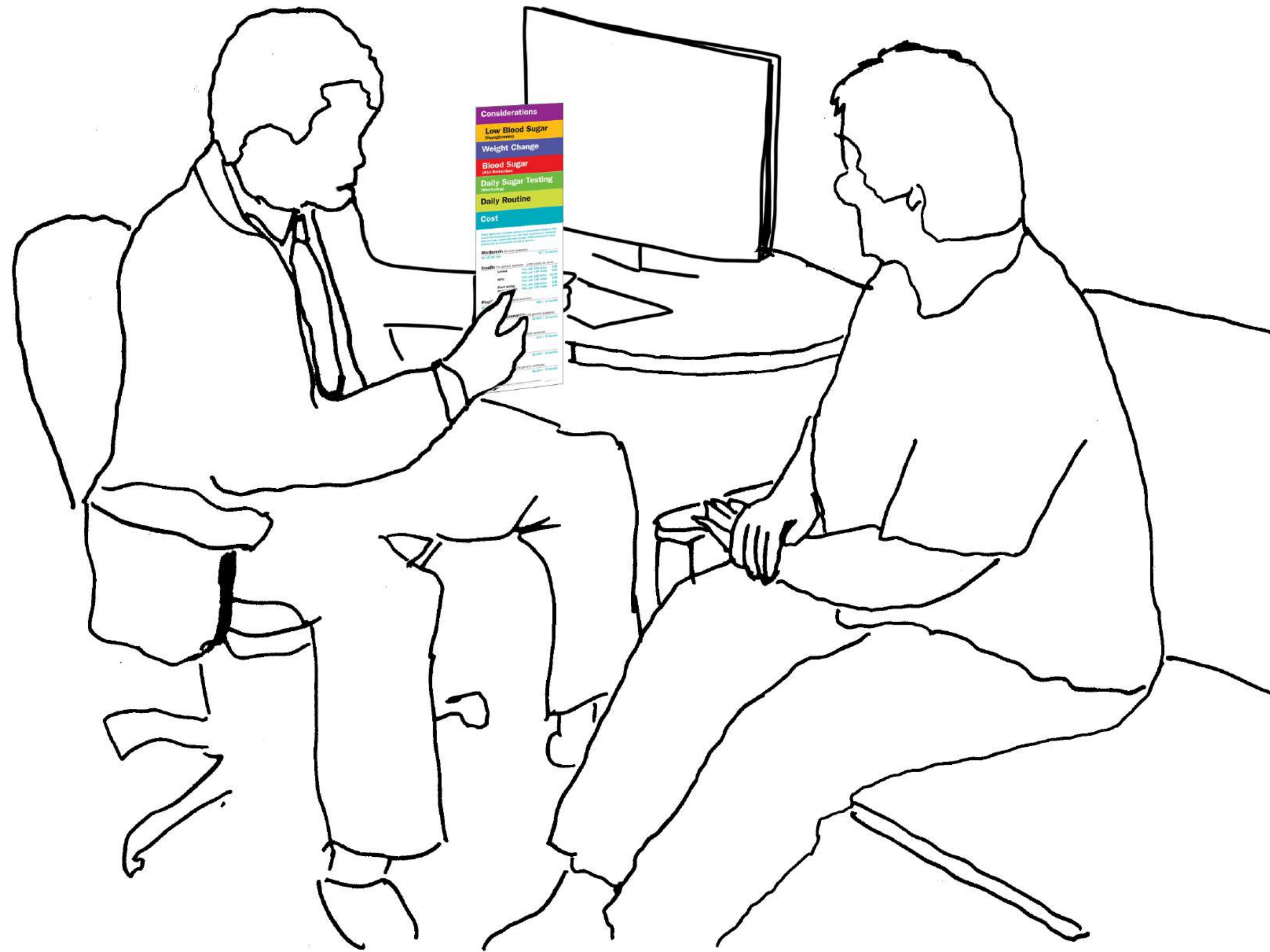
with Intervention



# Summary

- Age: 40-92 (avg 65)
- Primary Care, ED, hospital, specialty care
- 74-90% of clinicians want to use the tools again
- Adds ~3 minutes to the consultation
- 58% fidelity without training
- Effects on shared decision making are similar in vulnerable populations
- Variable effect on clinical outcomes and cost






92 year old patient story



Good interventions aim to create the  
conditions for care



## Quit for good.



Reasons you might choose to quit for good

**Good things about quitting for good**


- Having surgery increases the chances I will succeed in quitting
- I will heal better after surgery
- I will add years to my life

**Bad things about quitting for good**

- I enjoy cigarettes
- It can be hard to quit

*If you have thought about quitting for good, there is no better time than now that you are having surgery.*

## Quit for a bit.



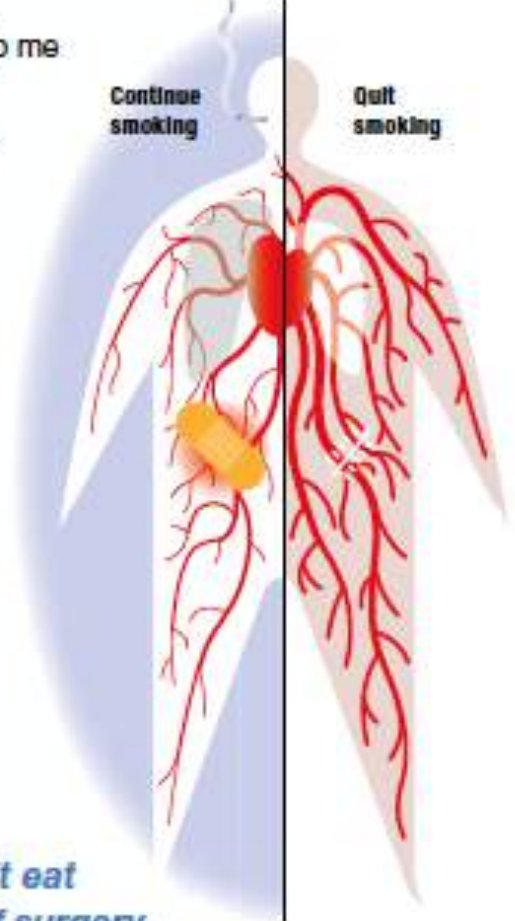
Reasons you might choose to quit smoking around the time of surgery

**Good things about quitting for a bit**

- Better healing after surgery
- Helps circulation
- No or mild cigarette cravings before and after surgery


**Bad things about quitting for a bit around the time of surgery**

- Cigarettes may help me cope with surgery
- I have other things to worry about
- Quitting can be hard



*Just like you don't eat on the morning of surgery, don't smoke — and stay off cigarettes for at least one week after your surgery.*

## Continue to smoke.



Reasons you choose not to quit

**Good things about continuing to smoke**

- I enjoy it
- It relaxes me
- It helps me cope

**Bad things about smoking around the time of surgery**

- Healing problems after surgery
- Breathing problems during surgery
- Circulation problems during and after surgery

*You may choose to keep smoking, but remember that you cannot smoke while you are in the hospital for your surgery.*

# Smoking Cessation around Surgery





What impacts  
the ability to  
notice and  
respond? to  
have a  
conversation?





Conditions for  
care are the  
product of:

**CULTURE**

**POLICIES**

**PROCESSES**

**SPACES**

## **CULTURE**

Shared ways of  
thinking and  
shared  
assumptions

## **POLICIES**

Laws, regulations,  
and incentives

## **PROCESSES**

Detailed actions  
and steps to  
achieve a  
particular end

## **SPACES**

Physical and  
virtual  
environments





## Point of Care

Space design  
Visit requirements  
Documentation requirements  
Lack of continuity

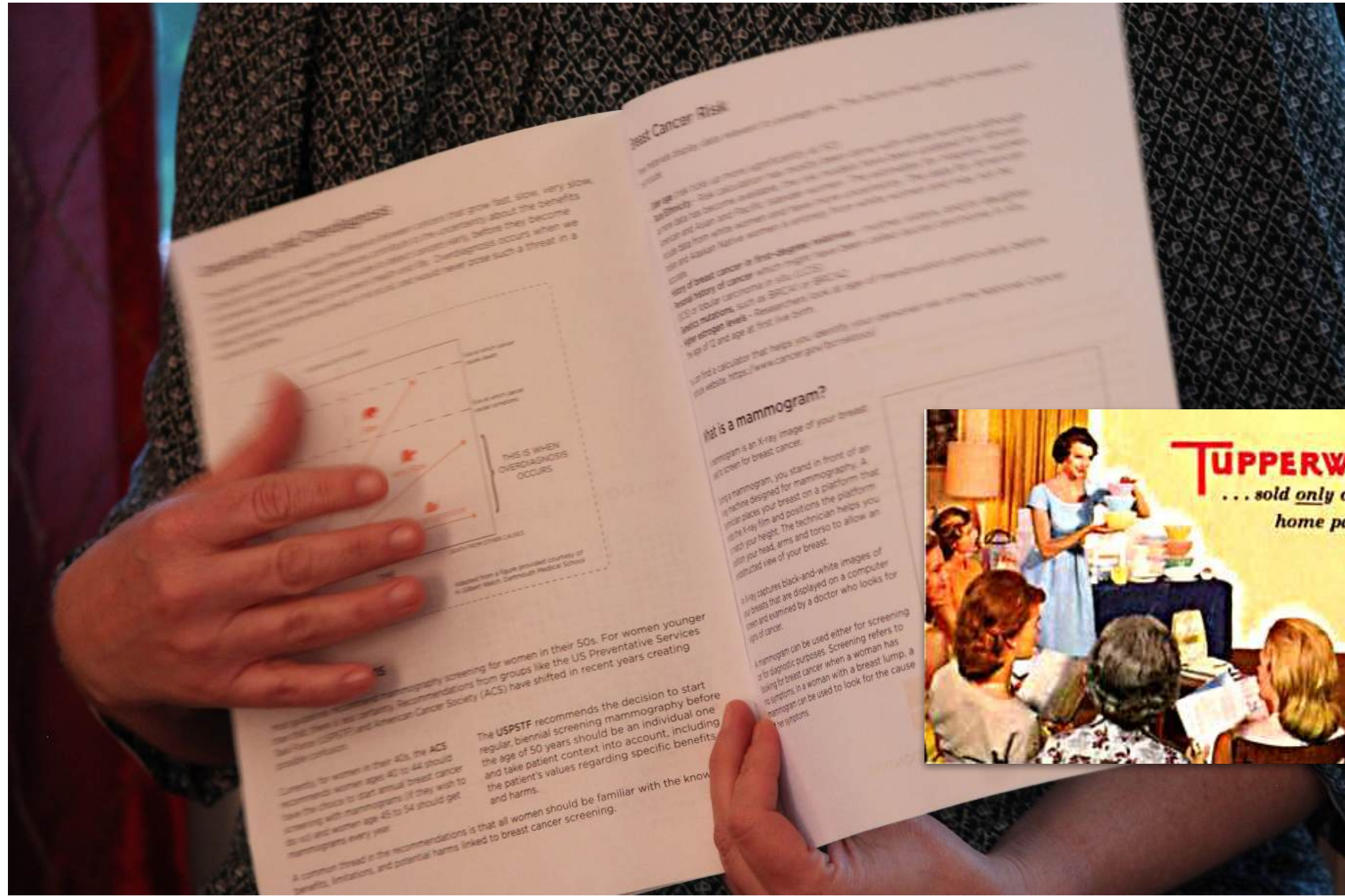
## Organization

Strategic priorities  
Payor contracts  
Assessment policies  
Performance improvement expectations

## Influence

Billing and payment policies  
Regulation  
Market expectations  
Malpractice and liability



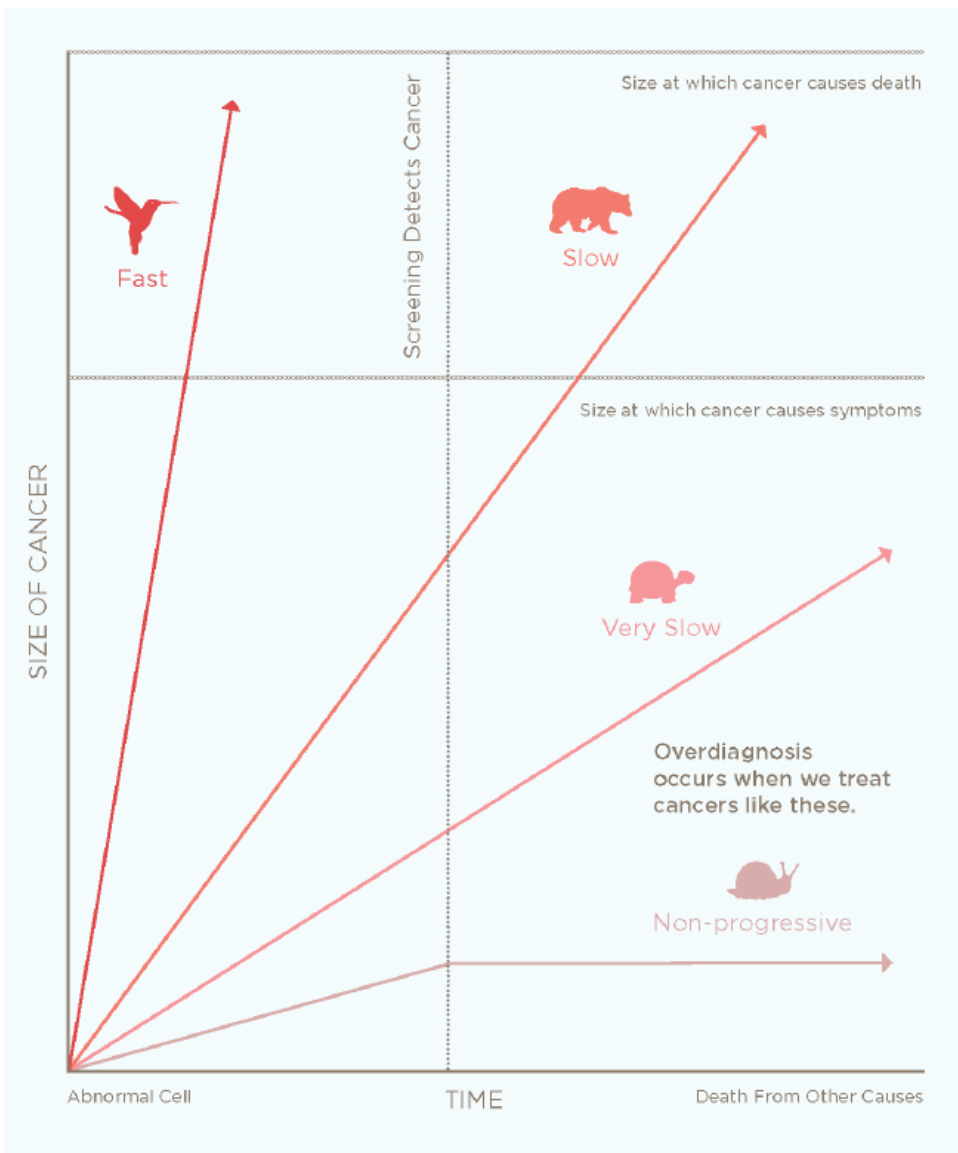


# Uncertainty and Overdiagnosis

This graphic attempts to show the difference between cancers that grow fast, slow, very slow, or that do not grow at all. These differences contribute to the uncertainty about the benefits of screening.

Ideally, we would like to be able to detect cancers early, before they become symptomatic or pose a threat to a woman's health and life. Overdiagnosis occurs when we detect cancers that grow very slowly, or not at all, and would never pose such a threat in a woman's lifetime.

What's Best for Me and My Family? – A Patient Revolution Event



Source: NCI Division of Cancer Prevention. Adapted from a figure provided courtesy of H. Gilbert Welch, Dartmouth Medical School



## Shared Decision Making as a method of care

“Anytime, a patient and clinician figure out together what to do about the patient’s situation, **they are doing SDM**.”

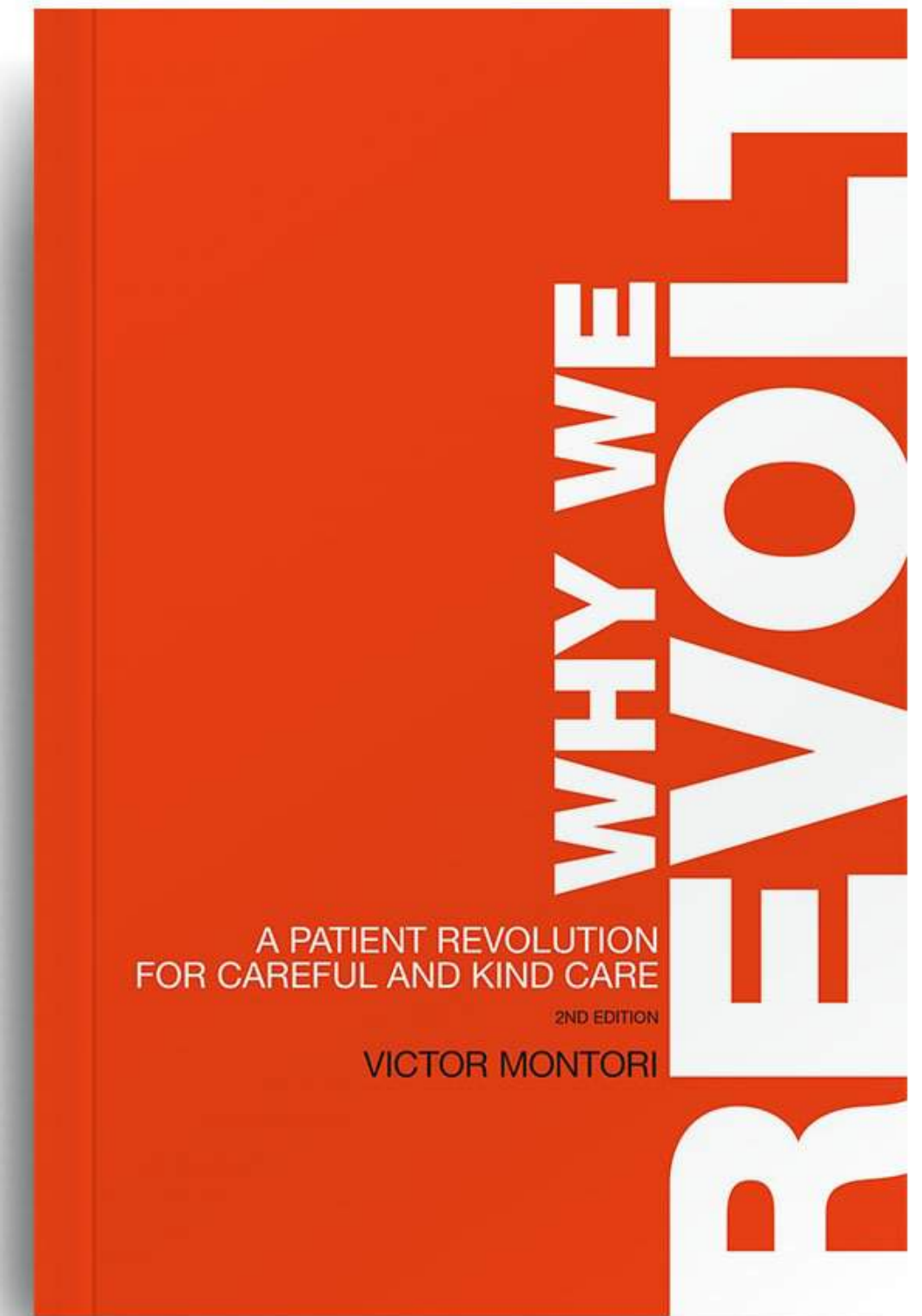
Therefore, we believe SDM is not ‘another thing clinicians must do’, that is, to help patients select the best evidence-based option given their preferences, but that it is a method of care, as central to the clinician’s art as history taking, the physical examination, the selection and interpretation of diagnostic tests, and patient education and counseling.”



Find more ways to get involved...

[patientrevolution.org](http://patientrevolution.org)

[maggie@patientrevolution.org](mailto:maggie@patientrevolution.org)



Foundations of Care course

