

DESIGN^{OF OUR ONLINE} WORLD

CCSQ WORLD USABILITY DAY 2021

Losing Patients

Trust, Compliance, and the Patient Journey

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- Author: *Data Insights: New Ways to Visualize and Make Sense of Data*
- Email: hunter.whitney@esimplicity.com

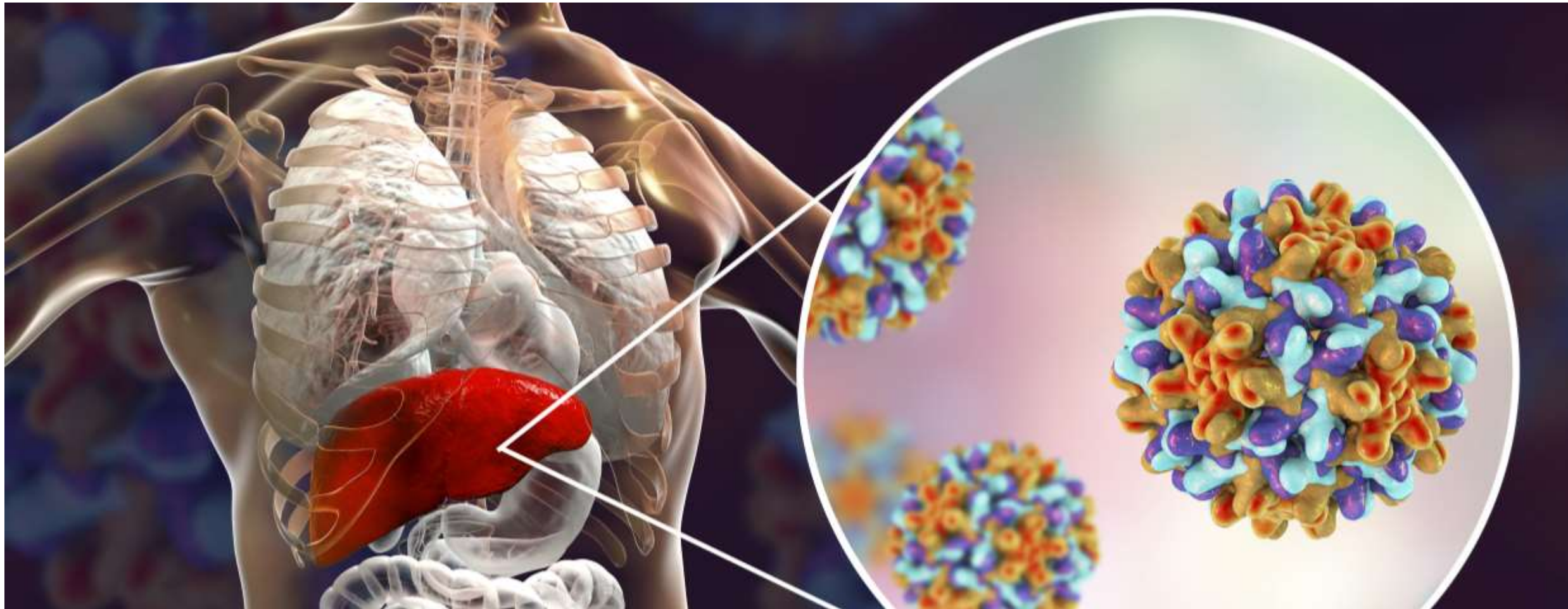


Challenge: How to Collect and Communicate health data that maximizes good outcomes and reduces cost?

(An HBV Treatment Decision Tool Design Case Study)

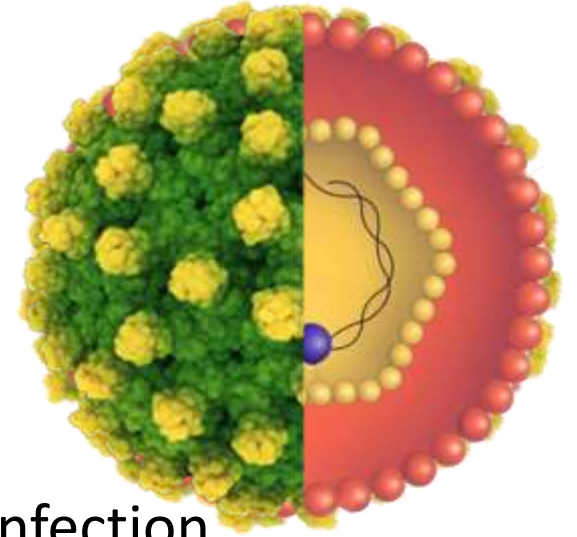
Why Hepatitis B is Interesting Test Case?

A model for other kinds of chronic disease management



The Hepatitis B Virus Infection

- Hepatitis B is a liver infection caused by the hepatitis B virus
- Two possible phases: **Acute/Chronic**
- 5-10% of adults
30-50% of children
90% of babies will not get rid of the virus and will develop chronic infection
- Chronic hepatitis B can quietly attack the liver for years without causing any symptoms



Chronic HBV Infection is Among the Greatest Racial/Ethnic Health Disparities in the U.S.

880,000 people living with HBV in the US, modeled estimate 1.4-2.4 million

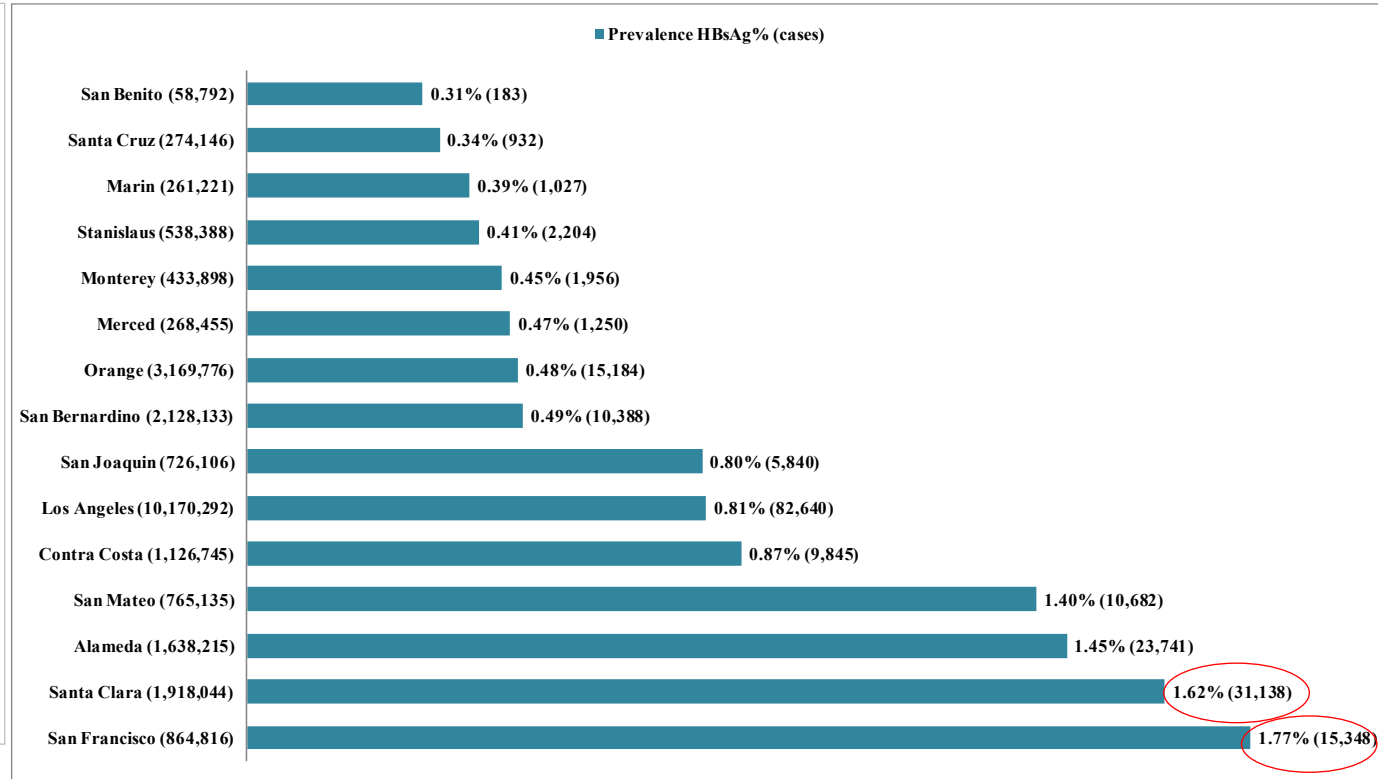
Racial/Ethnic Population	Prevalence of Chronic HBV Infection
Asian and Pacific Islander (foreign born)	1 in 12
Asian and Pacific Islander (US born)	1 in 70
African American	1 in 200
Hispanic	1 in 1,100
Non-Hispanic White	1 in 800

Source: CDC draft ACIP recommendations, 2018
Roberts et al. 2021, Wong et al. 2021 Hepatology

APIs make up 5% of the U.S. population, but account for over **60%** of chronic HBV cases

10 Most Common Causes of Death from Cancer in API Men in the U.S.

1. Lung and bronchus
- 2. Liver**
3. Colon and rectum
4. Prostate
5. Stomach
6. Pancreas
7. Non-Hodgkin lymphoma
8. Leukemia
9. Esophagus
10. Brain



San Francisco and Santa Clara counties have one of the highest incidence of liver cancer in the country (West Coast)

New York City has a prevalence of 2.7% representing 230,000 persons (East Coast)

Source: US Cancer Statistics: 2013 Incidence and Mortality Web-based Report.
 Available at nccd.cdc.gov/uscs
 Toy et al. Racial/Ethnic- and County-Specific Prevalence of Chronic Hepatitis B and its Burden in California. *Hepatol Med Policy*. 2018
 Moore et al. Surveillance-Based Estimate of the Prevalence of Chronic Hepatitis B Virus Infection, New York City, 2006. *Public Health Rep*. 2019

Diagnosis and Treatment

- Diagnosed with blood tests
- Hepatitis B surface antigen (HBsAg) is most frequently used to screen for presence of infection
- Firstline treatment is entecavir or tenofovir
- Drugs can stop the virus from replicating to prevent the progression of the disease to cirrhosis, or liver cancer



Monitoring and Linkage to Care

- CHB is a chronic infectious disease that needs ongoing care such as monitoring for liver enzymes and HBV DNA tests in treated and untreated patients, and annual imaging evaluation for liver cancer.
- **2/3** who are aware of their infection are not seeing a healthcare provider!

Barriers

- Patient
- Provider
- Health Systems

Ispas et al. 2019. Barriers to Disease Monitoring and Liver Cancer Surveillance Among Patients with Chronic Hepatitis B in the United States. *Journal of Community Health* 44:610-625.



Hepatitis B Screening in the US

- **The Centers for Medicare & Medicaid Services (CMS)** has determined that the evidence is sufficient to conclude that screening for HBV infection, consistent with grade A and B recommendations by USPSTF, is reasonable and necessary
- **CMS** will cover screening for HBV infection in “high risk” individuals, and in a first prenatal visit for pregnant women
- HBV is a great example for reducing healthcare costs down the line

UnitedHealthcare Medicare Advantage Policy Guideline. Screening for Hepatitis B Virus (HBV) Infection (NCD 210.6). June 9, 2021

Distrust and Patient Non-Compliance

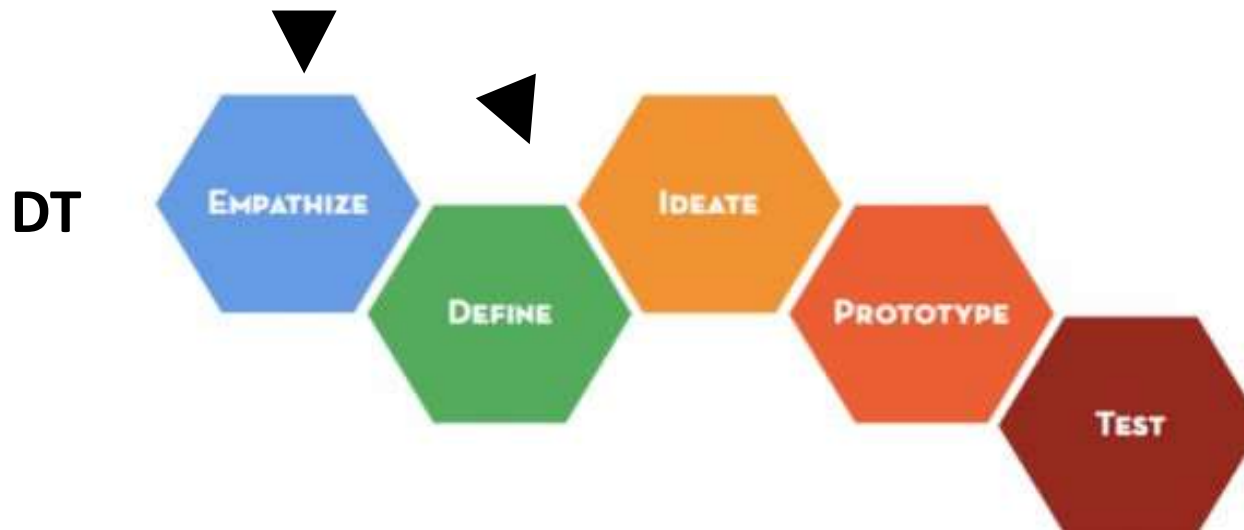
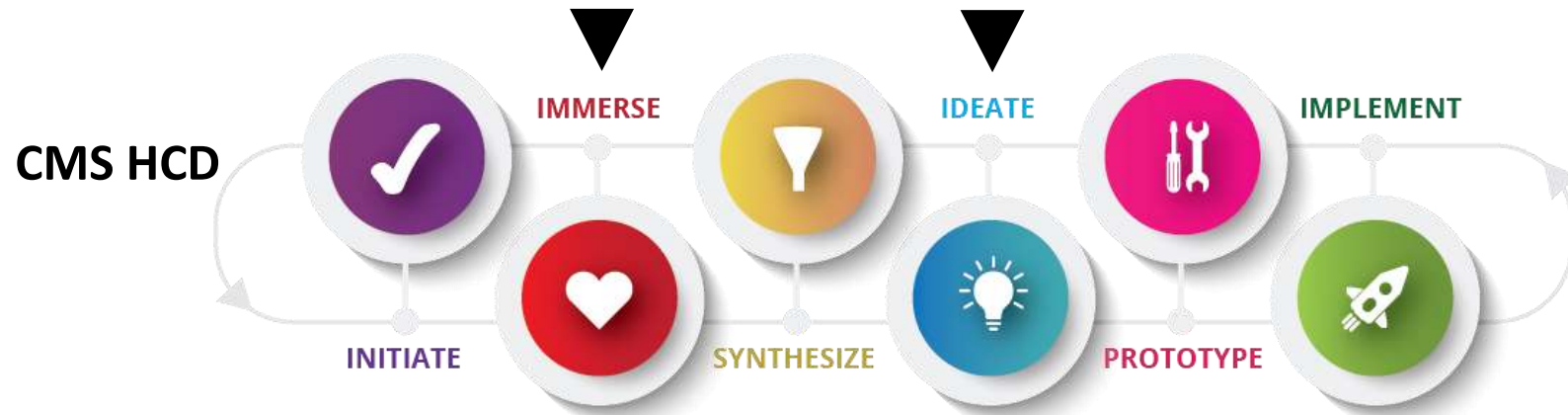
- We cannot take for granted that all developments in medicine are understood or even accepted by everyone
- Effective communication of **risk** and **benefit** information
- Research suggests that the format of quantitative information can be a source of confusion
- Human-Centered Design plays a major role. We're going to talk about the HBV Treatment Decision Prototype in a just a little bit, but first some HCD context

HCD: Putting Hep B Treatment Decision in Human Terms

CMS HCD Process and Design Thinking

“While different frameworks for design thinking exist, they all focus on customer empathy and engagement as a way to solve the right problem the right way.”

-CMS HCD Process page



Problem Framing for Patients *and* Providers



Archetypes and Personas for Compliance Strategies

Archetypes and Personas can help identify where and how to reach focus communications strategies

Low motivation, low trust



Medium motivation, High trust



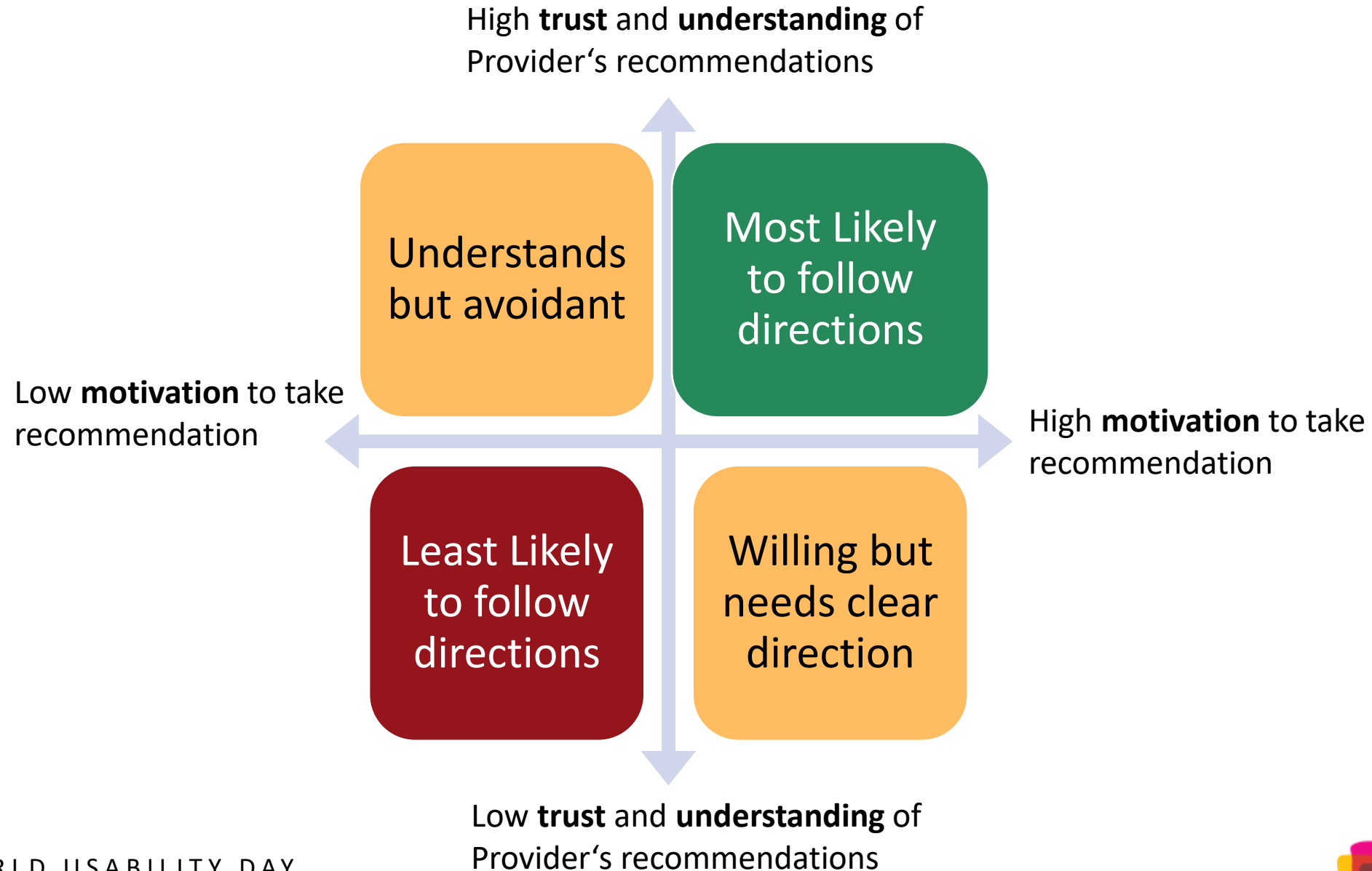
High motivation, high trust



High motivation, lower trust



Provisional Archetype Matrix



Potential Social and Cultural Drivers of Compliance

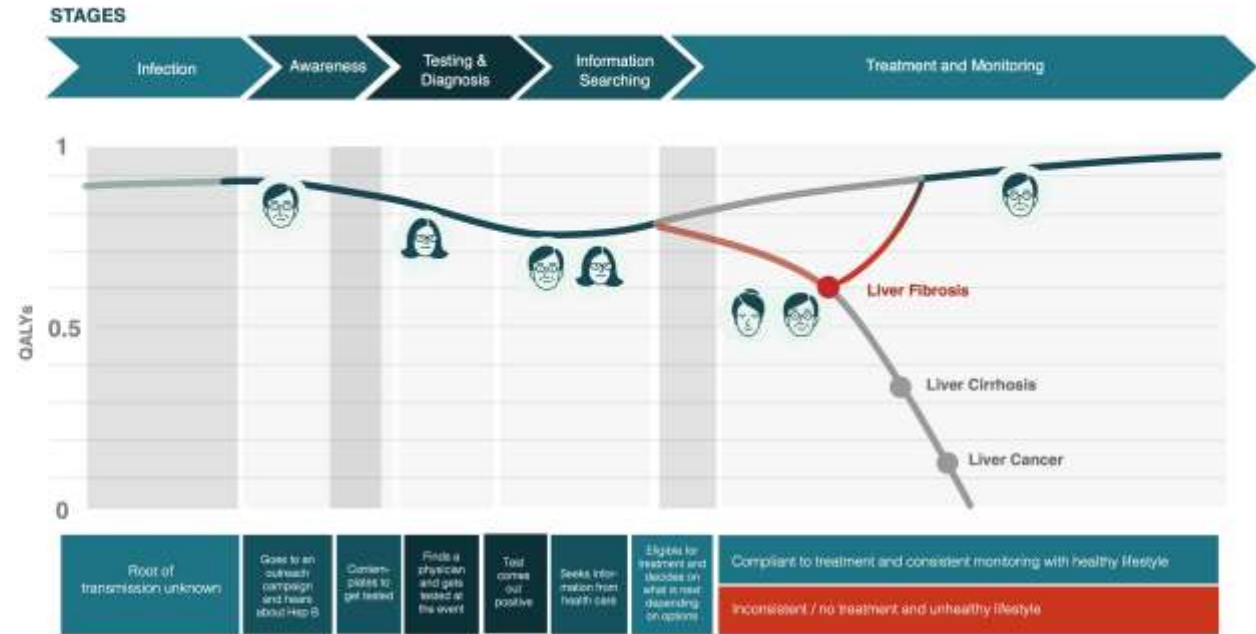


Inflection Points

The outcome of a Hep B infection can depend on many factors including

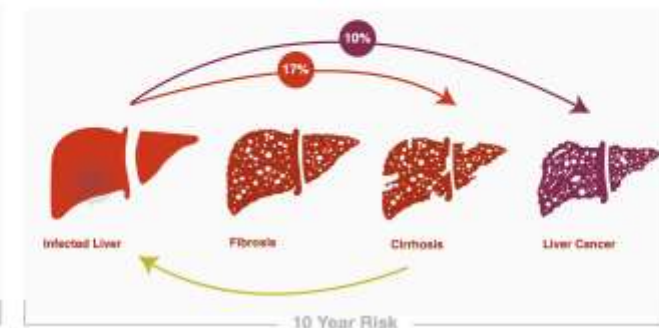
- Psychological factors -
- Information quality, relevance, and resonance with the patient
- Medical and social support
- Timing of check-ins and potential interventions

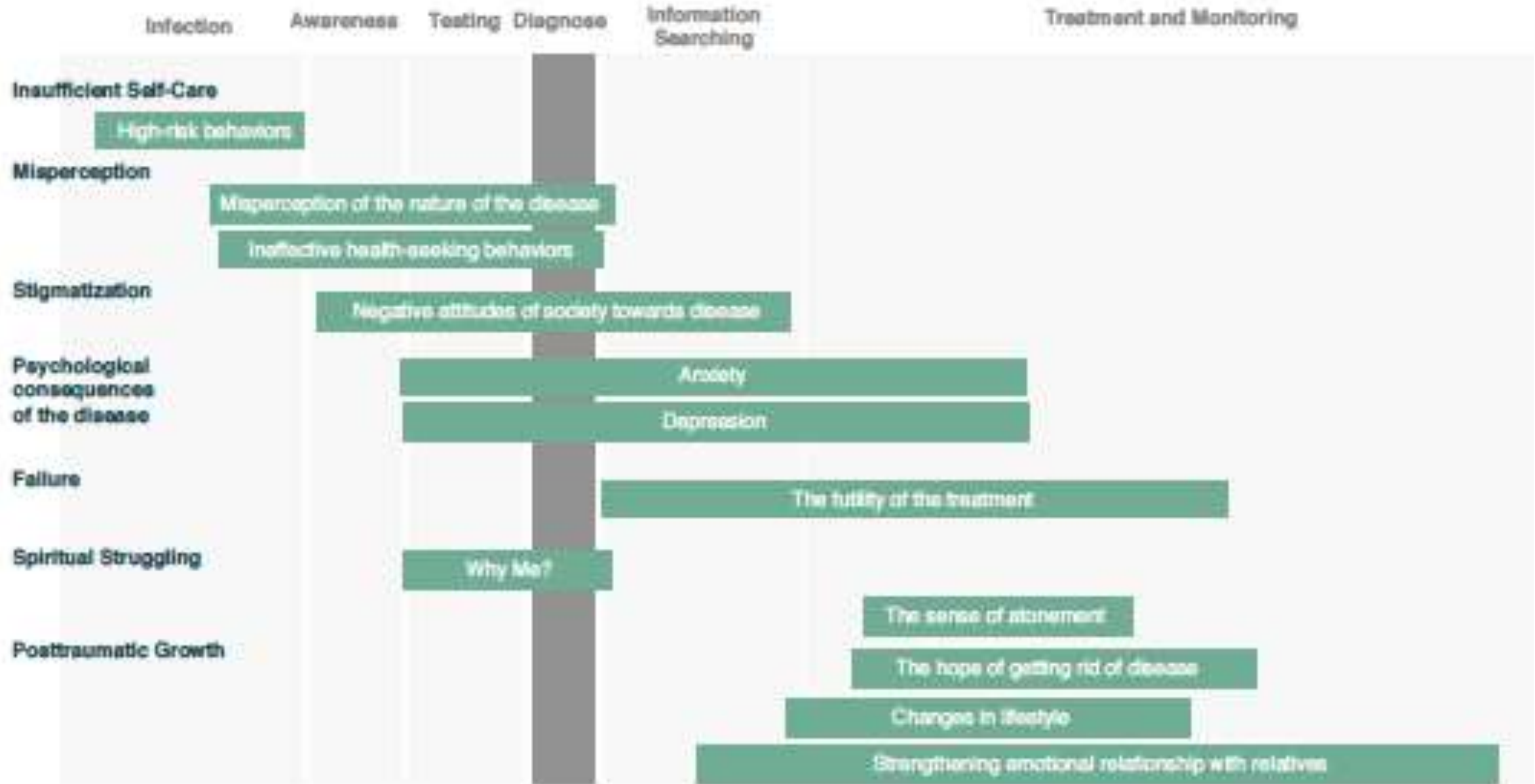
HEP B PATIENT JOURNEY MAP



QALYs - Quality Adjusted Life Years

Individual moves through "health states" over time, with 1 representing a subjective feeling of "perfect health" and 0 signifying death.







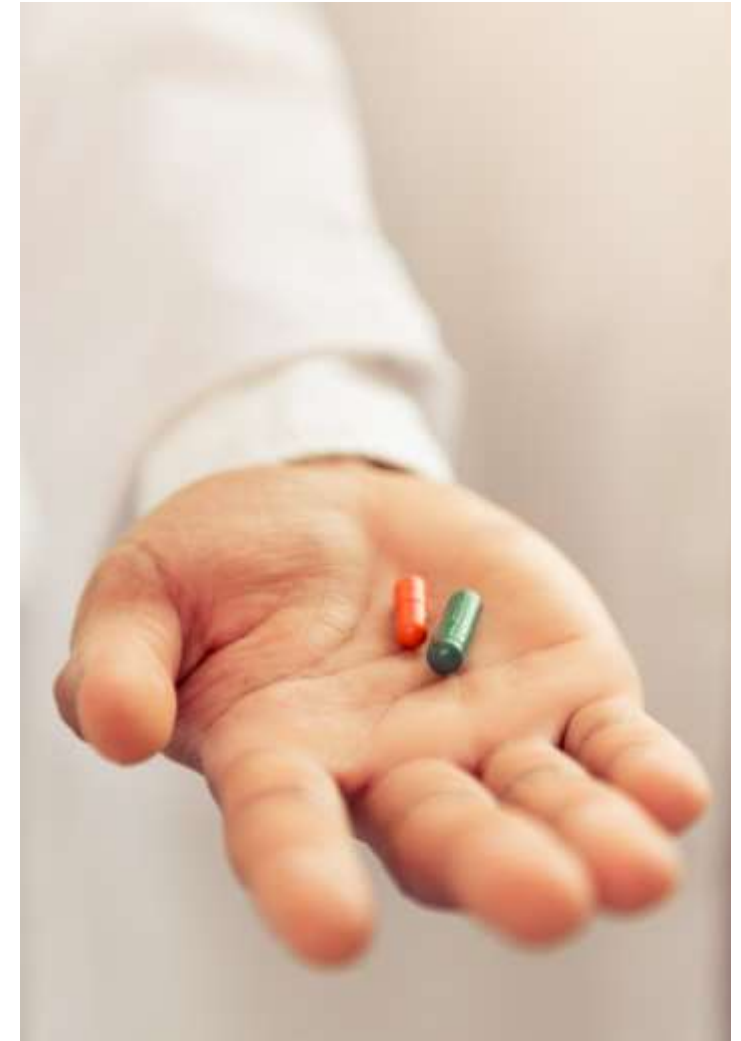
Empathy is Foundational for Human-Centered Design

Here's a story of Applied Empathy...

Life-Saving Technology can be Forbidding



You Could Take One of these Approaches





The Human Experience

- ~~Patient~~
- ~~Customer~~
- Frightened Child

An Effective, Lower Cost Approach from HCD



Applied Empathy has Practical Value



Uncertainties (Medical Decision Making)

- Diagnosis
- Accuracy of available diagnostic tests
- Natural history of disease
- Treatment effects on individual patient/intervention on population

- Uncertainties associated with the decision problem
- Find best available evidence to support or refute your assumptions

Prototype HBV Treatment Decision Tool

Global Prevalence of Chronic Hepatitis B Infection

1. What is the **endemicity** of your patient's country?
Refer to the map above for reference.

- High - Intermediate High (>5%)
- Intermediate Low (2% - 5%)
- Low (<2%)

2. What is your patient's age?

3. Does your patient have **Cirrhosis**?

- Yes
- No

4. If your patient does not have Cirrhosis, what is your patient's **ALT** level?
Abnormal: Under 60 U/L for men & under 38 U/L for women
Normal: Under 30 U/L for men & under 19 U/L for women

- Persistently Abnormal
- Intermittently Abnormal
- Persistently Normal

5. What is your patient's HBV DNA level?
Units in IU/mL.

- >20,000 IU/mL
- 2000-20,000 IU/mL
- <2000 IU/mL

SUBMIT

YOUR RESPONSES

Your 45 year old patient doesn't have Cirrhosis with a Intermittently Abnormal ALT level and an HBV DNA level that is <2000 IU/ml.

Mortality Rate HBV

Liver Cancer

Cirrhosis

NATURAL HISTORY | TREATMENT

Years	DeathHBV NH	DeathHBV Rx	Liver Cancer NH	Liver Cancer Rx	Cirrhosis NH	Cirrhosis Rx
5	1.13%	0.65%	1.35%	1.01%	1.35%	0.78%
10	3.77%	1.75%	3.5%	2.24%	3.77%	1.57%
20	11.77%	4.4%	9.08%	4.94%	9.16%	2.75%
40	24.86%	8.44%	17.47%	8.91%	15.73%	3.75%

Prototype

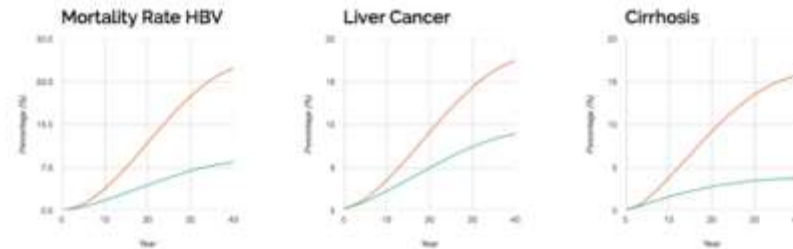
Patient: John Smith
Physician: Mary Chan
Date: March, 3, 2017

Dear Mr. Smith,

Thank you for filling out the chronic hepatitis B disease risk questionnaire. The table and figures below show your responses to the questionnaire and the outcomes according to your responses. This table and figures were also provided to your physician.

YOUR RESPONSES

Your 45 year old patient doesn't have Cirrhosis with a Intermittently Abnormal ALT level and an HBV DNA level that is <2000 IU/ml.



NATURAL HISTORY | TREATMENT

Years	DeathHBV NH	DeathHBV Ra	Liver Cancer NH	Liver Cancer Ra	Cirrhosis NH	Cirrhosis Ra
5	1.13%	0.63%	1.30%	1.01%	1.30%	0.78%
10	3.77%	1.75%	3.5%	2.24%	3.77%	1.57%
20	11.77%	4.4%	9.08%	4.94%	9.16%	2.75%
40	24.88%	8.44%	17.47%	6.91%	15.73%	3.75%

Your responses to these questions indicate that you are at risk for liver cancer and cirrhosis. These risk factors are related to your age, your ALT and HBV DNA levels, and status of cirrhosis.

You are advised to be monitored for your ALT and HBV DNA and also bi-annually an ultrasound for liver cancer surveillance.

HCD Lens

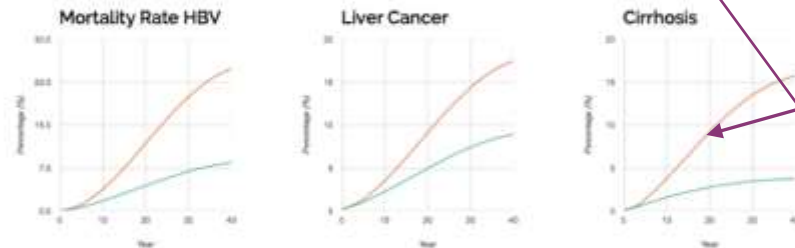
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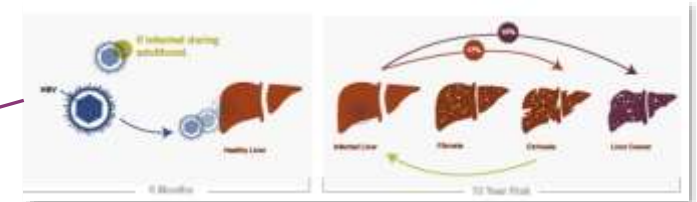
NATURAL HISTORY | TREATMENT

Years	DeathHBV NH	DeathHBV Rx	Liver Cancer NH	Liver Cancer Rx	Cirrhosis NH	Cirrhosis Rx
5	1.13%	0.03%	1.33%	1.01%	1.30%	0.78%
10	3.77%	1.75%	3.5%	2.24%	3.77%	1.57%
20	11.77%	4.4%	9.08%	4.34%	9.16%	2.75%
40	24.88%	8.64%	17.47%	6.91%	16.73%	3.75%

Your responses to these questions indicate that you are at risk for liver cancer and cirrhosis. These risk factors are related to your age, your ALT and HBV DNA levels, and status of cirrhosis.

You are advised to be monitored for your ALT and HBV DNA and also bi-annually an ultrasound for liver cancer surveillance.

Other kinds of visuals to make "silent killer" more tangible?



- Language
- Simplicity
- Psychological impact
- Motivation
- Usefulness

Recommendation placement?

HBV Treatment Cost Tool (Separate Use Case)



HOME ABOUT THE CALCULATOR THE TEAM

The Hep B Calculator

[Click here to print](#)

Country

-
-
-
-
-
-
-

Inputs

conversion: \$1 USD = Rupiah

Annual Cost	Amount in US\$
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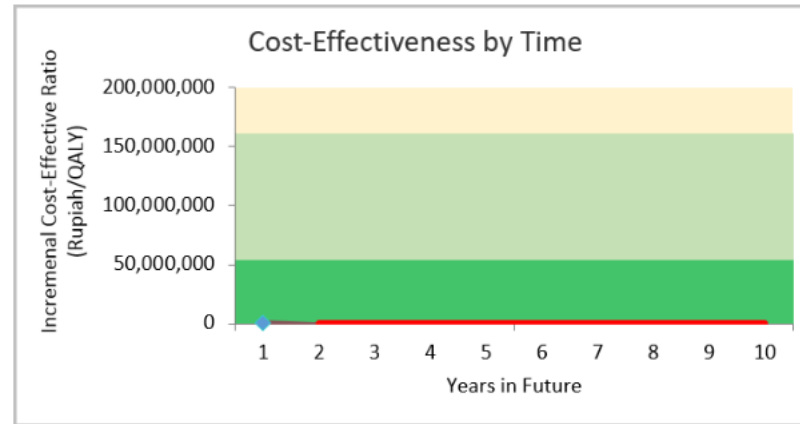
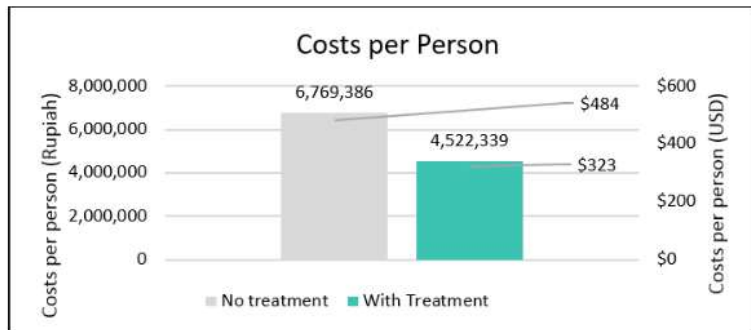
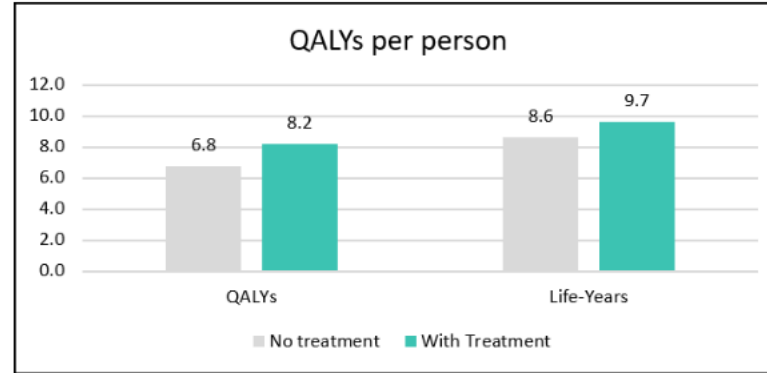
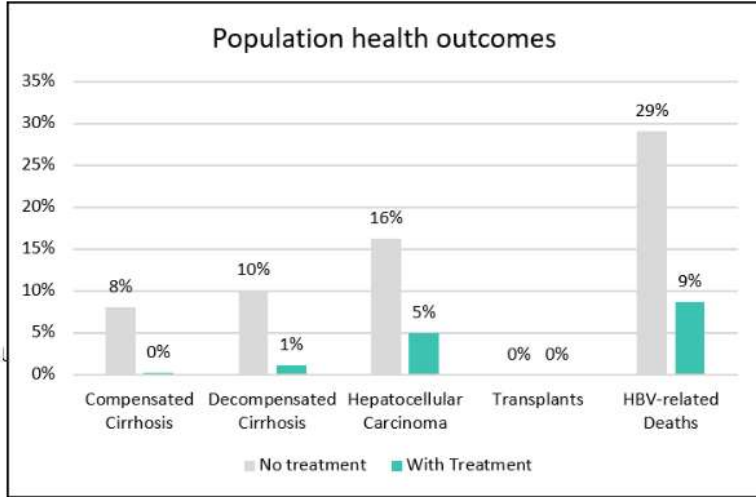
Chronic Hepatitis B (F0-F3)	210,000	\$ 15
Compensated Cirrhosis	840,000	\$ 60
Decompensated Cirrhosis	4,858,000	\$ 347
Hepatocellular Carcinoma	6,048,000	\$ 432
Liver Transplant (year 1)	-	\$ -
Liver Transplant (year 2+)	-	\$ -
Antiviral Drug Cost	378,000	\$ 27

Annual Probability of Transplant

with Decompensated	<input type="text" value="0"/>
with Hepatocellular	<input type="text" value="0"/>

Time Horizon (years) (max 50)

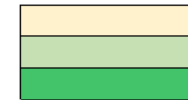
HBV Treatment Cost Tool (Separate Use Case)



The WHO suggests that if this ICER is above three times the country's GDP per capita, the intervention is considered to be "not cost-effective". If an intervention's ICER is between one times the country's GDP per capita and three times the country's GDP per capita, the intervention is considered to be "cost-effective". If the intervention's ICER is below one times the country's GDP per capita, the intervention is considered to be highly cost-effective (a low cost to "purchase" the QALYs gained).

Cost-Saving: An intervention is considered cost-saving if it both saves costs (summed over the time horizon) and improves health.

Not Cost-Effective
 Cost-Effective
 Highly Cost-Effective
 Cost-Saving



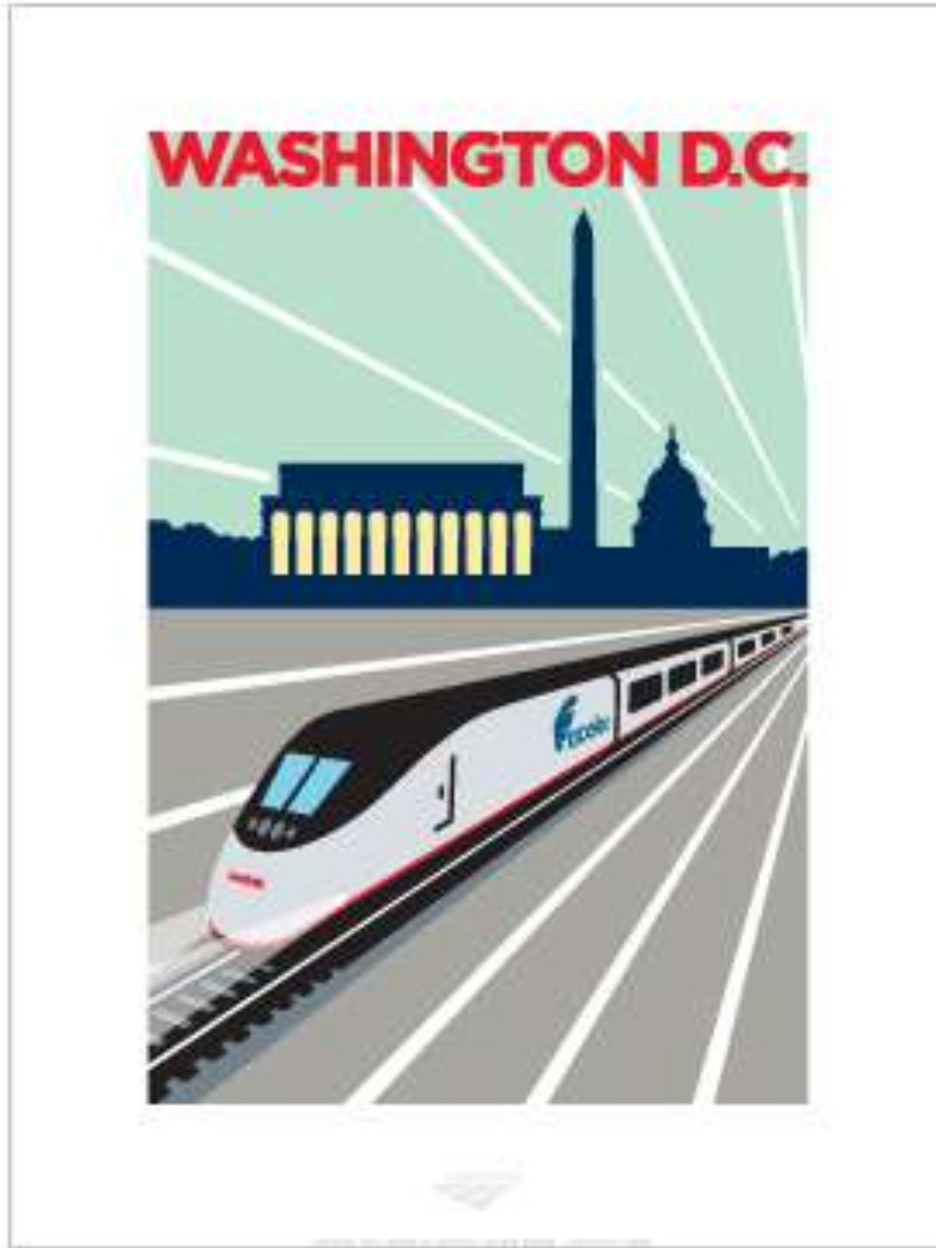
IF the line goes to zero (red), it is cost-saving

*highly-cost effective = $(ICER < GDP/Capita)$

* cost-effective = $(ICER < 3x GDP/Capita)$

GDP per capita is:

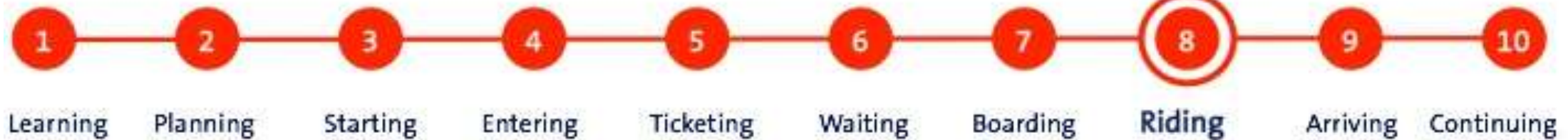
53,856,600 Rupiah per year



Avoiding One Track Thinking

- Service Design takes into account many touchpoints in a journey
- Too much focus on a single touchpoint can undermine overall success

Totality of Experience



Too much focus here ignores the totality of the customer experience

<https://ludensfaber.wordpress.com/2014/01/15/the-amtrak-acela-customer-experience-hair-on-my-seat/>

For example: There was no car rental facility at the Rt. 128 terminus, so Acela had to delay opening until it could be established.

What is the probability of breast cancer for a woman over 40 who has a positive mammogram?



“Many doctors have trouble distinguishing between the sensitivity, the specificity, and the positive predictive value of test—three conditional probabilities. Again, the solution lies in the representation.”
-Gerd Gigerenzer

[BMJ](#). 2003 Sep 27; 327(7417): 741–744.
doi: [10.1136/bmj.327.7417.741](https://doi.org/10.1136/bmj.327.7417.741)

Cognitive Biases, Data, and Test Results

“The common human tendency to rely too heavily on the first piece of information offered (the "anchor") when making decisions.”

- Wikipedia

Sensitivity vs. Specificity Distinctions and Anchoring

	Has Breast Cancer	Doesn't Have Breast Cancer	TOTAL
+ Mammogram	(a) 8	(b) 95	103
- Mammogram	(c) 2	(d) 895	897
TOTAL	10	990	1000

Sensitivity = $a/(a+c) = 8/(8+2) = 80.0\%$

Specificity = $d/(b+d) = 895/(95+895) = 90.4\%$

False Positive = $95/1000 = 9.5\%$ More likely to over diagnose than under diagnose

False Negative = $2/1000 = 0.2\%$

Positive Predictive Value (PPV): the probability that a patient with a positive test result really does have the condition for which the test was conducted. $PPV = a/(a+b) = 8/(8+95) = 7.8\%$

Negative Predictive Value (NPV): the probability that a patient with a negative test result really is free of the condition for which the test was conducted.

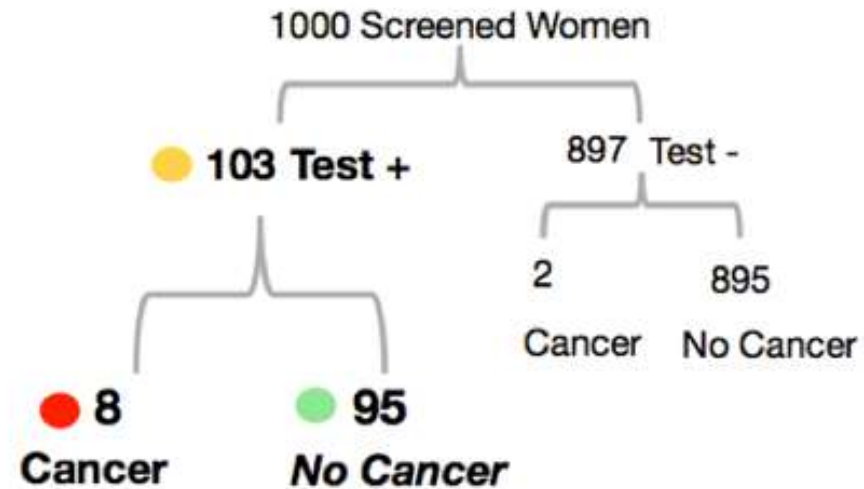
$NPV = d/(c+d) = 895/(2+895) = 99.8\%$

Framing the Data for Patient *and* Provider

- **Conditional Probabilities** are not as well understood, and communicated, relative to **Natural Frequencies** and **Simple Visualizations**

“Visual representations may substantially improve comprehension of risk.”

-Gerd Gigerenzer

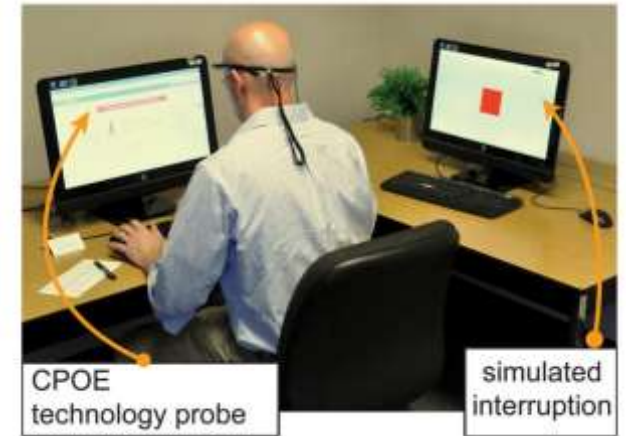
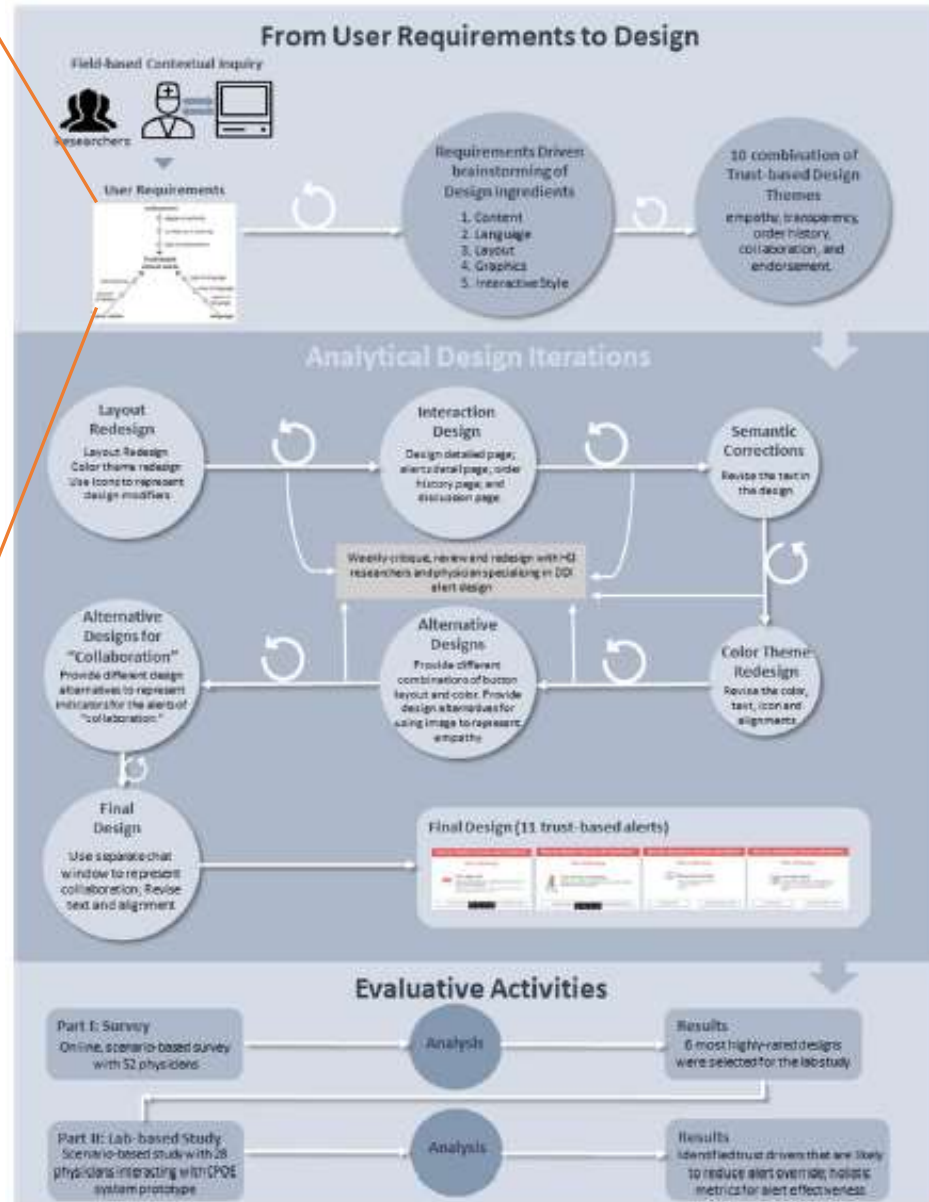
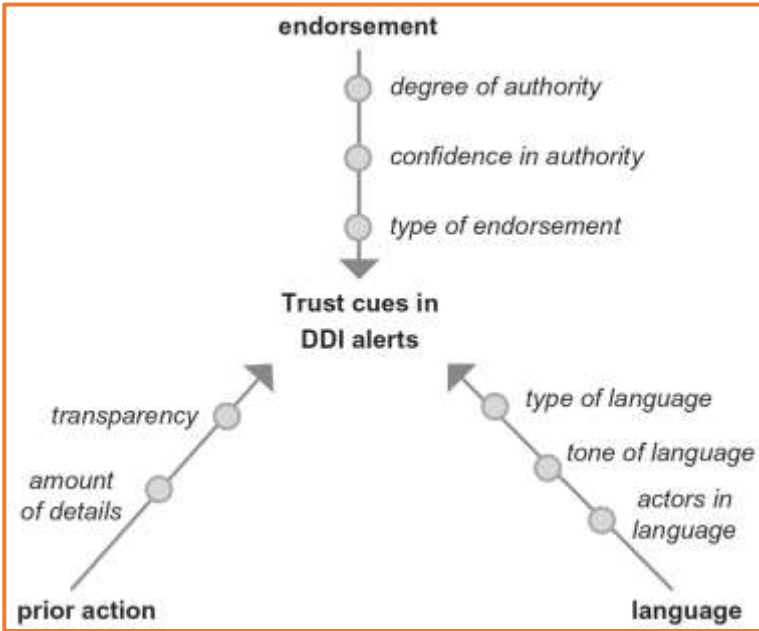


The actual probability that Nancy has cancer is:

$P = \frac{8}{103}$ or **7.8%**

...that's not trivial, but it's far less than 80% that the physician initially thought.

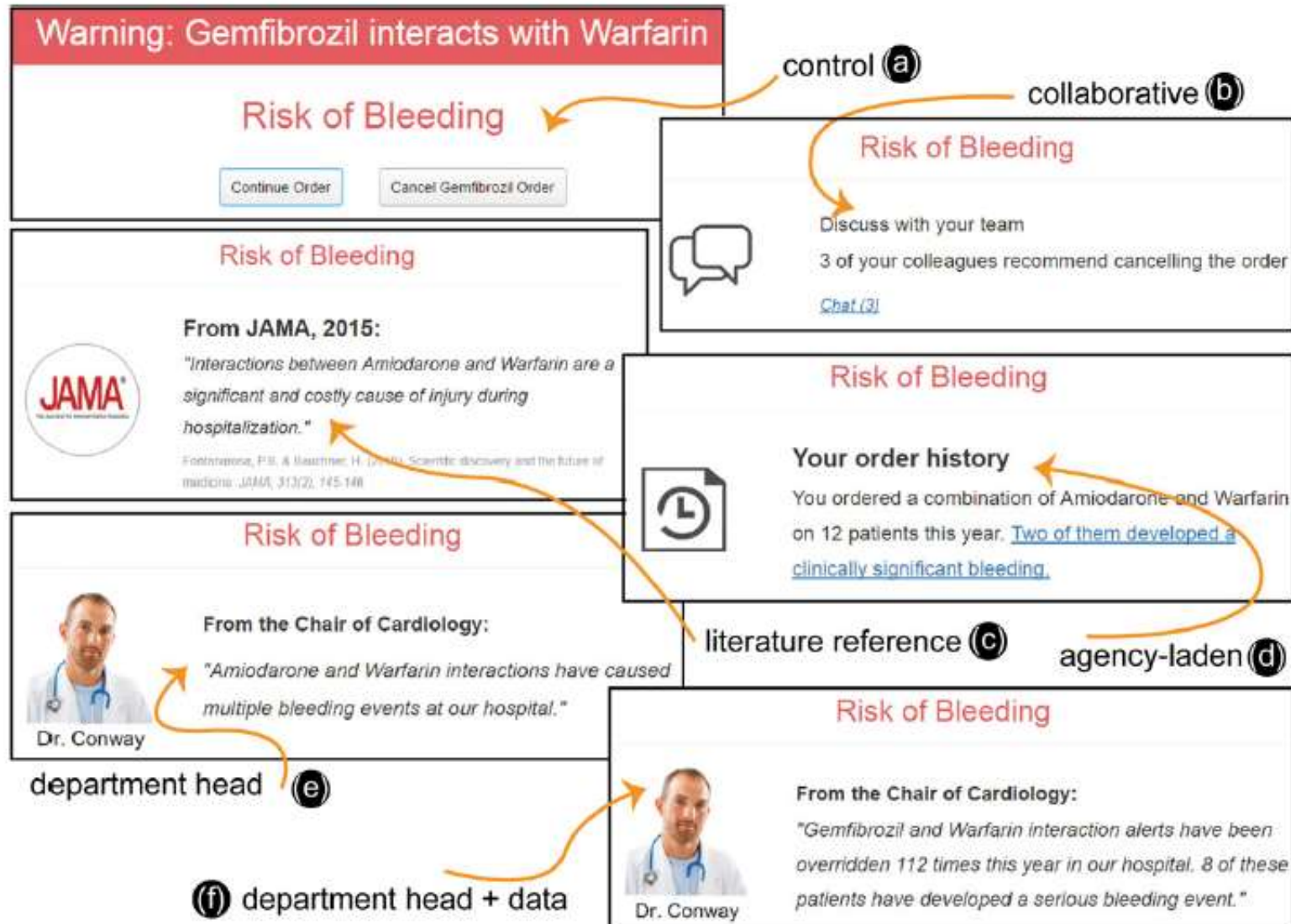
Trust Cues Example: Drug-Drug Interaction Alert Design



Jon Duke, MD Director, Center for Health Analytics and Informatics @ Georgia Tech

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doi:10.1093/iwc/iwx020

Trust Cues Example: Drug-Drug Interaction Alert Design



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doi:10.1093/iwc/iwx020

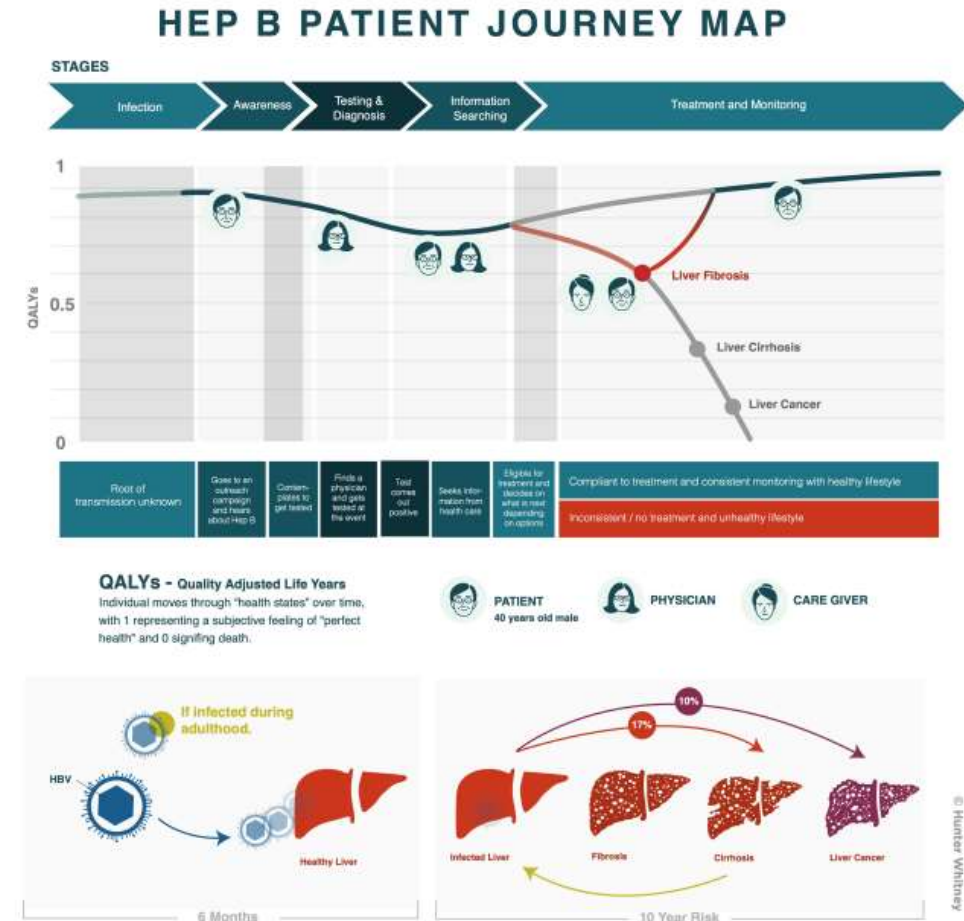
Empathy, Gut-Checks, and Ideation

- Empathy means being able to imagine yourself in someone else's shoes. However, drawing upon relevant experience in your own shoes can help drive design HCD ideation
- Building a relationship with your health data e.g.,
 - Health tracker
 - Something to put on the refrigerator
 - Peer Support



Design Themes/Ideation Including...

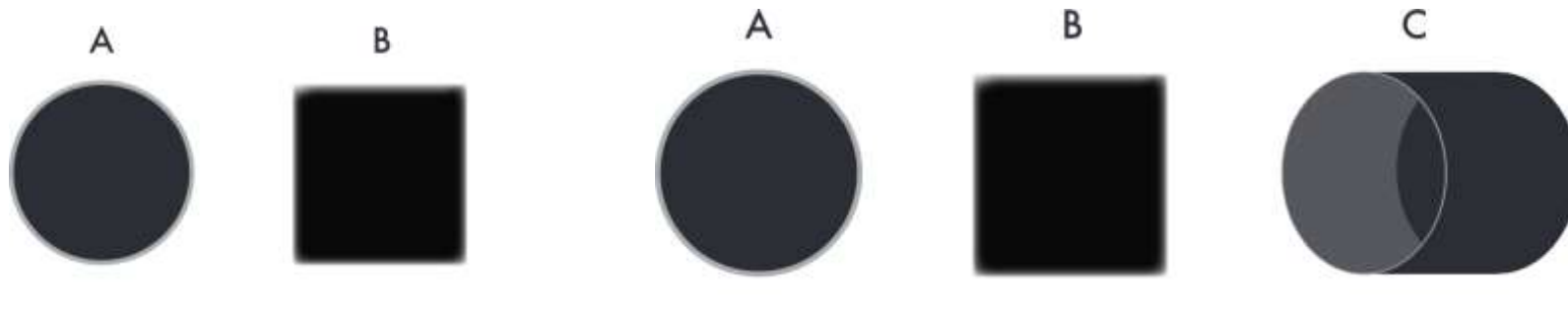
- Improving clarity and usability of health data communications for all in the ecosystem
 - For Patients, Providers, and Care Givers
 - Emerging channels, telemedicine, mobile devices and wearables
- Personal ownership of data
 - HCD-Informed data collection and targeted communication strategies
 - Improving clarity and actionability of data and care regimens
 - Flexibility, negotiation, and trade-offs
 - Allow for exploration of personal data
 - Reminders
 - Third party health apps
- Informational Social Influence “Social Proof”
 - Telling the story through data about other people with similar symptoms, age ranges, backgrounds, or other ‘people like me’ types of statistics?



Conclusion

Next Steps...

There was a lot here! The point is to not make it overwhelming, but to make a clear, *complete* perspective to design better systems and outcomes!



We appreciate the opportunity to share our early work to raise awareness and get your perspectives. We invite collaboration and support.

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Georgia Tech Research Institute (GTRI)
Principal Research Scientist

UC Berkeley Ext - HCD for Data Visualization students:

- Carrie Doung
- Ben Blout
- Sadie Koehler
- Sarah Coulter

Our HCD Mindset (1 of 2)

- **Do** - define *concretely* the people and contexts for which the data will be used
- **Don't** - underestimate the influence of human psychology, including bias, at all stages of the data lifecycle

- **Do** - see empathy can be a practical, problem-solving tool even in data analytics
- **Don't** - assume that your audiences think the way you do about the data

- **Do** - develop a general awareness of the entire data lifecycle and not just your part in it
- **Don't** - assume that the data you have is necessarily complete and correct

- **Do** - allow for flexibility for how people work with data
- **Don't** - allow flexibility to be an excuse for not thinking about ways to streamline and help guide your audiences through a process

- **Do** - find ways to connect and track data from collection to display and analysis.
- **Don't** - allow artificial silos to obscure the context and big picture of your data

Our HCD Mindset (2 of 2)

- **Do** prioritize what you display to your users based on an understanding of them and their needs
- **Don't** unintentionally distort the the data by inappropriate design choices

- **Do** - consider that small interaction design issues like sluggish performance can influence data workflows and the analytic experience
- **Don't** - forget that the data dashboard is not goal - it's the experiences, insights, and actions

- **Do** - try to simplify the process of working with data
- **Don't** - *oversimplify* (defining your audience will help you determine the right level)

- **Do** - try to be open to different solutions to a challenge at the start, even to the occasional seemingly counter-intuitive ones
- **Don't** - mentally lock down on one idea too soon

- **Do** - test your ideas with users in real-world contexts
- **Don't** - forget that design thinking is an iterative process

**THANK
YOU!**

Data Trade-offs and Ethical Design Considerations

- The ability to collect and use More Hep B data
 - Comprehensiveness/Accuracy vs Privacy/Intrusiveness
 - Inequity reaching different patient populations