From Personal Data to Personal Health: Tools to Reduce Burden & Improve Collaboration

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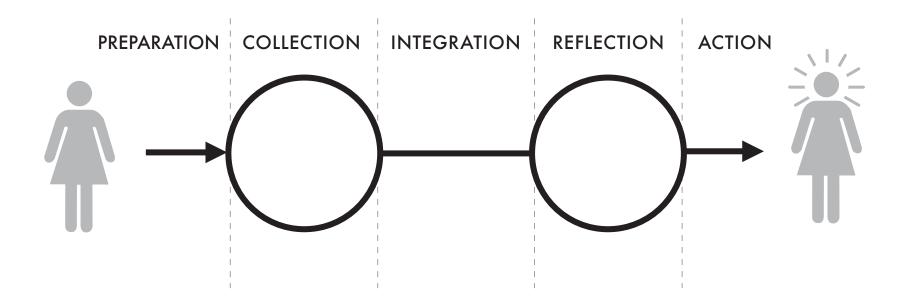




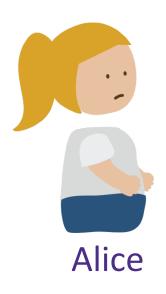




Five-Stage Model of Personal Informatics

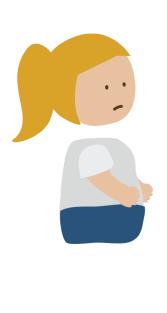


Five-Stage Model of Personal Informatics



- 20 years old
- Has a family history of heart disease
- Wants to be more active
- Does not know how, because she is busy

Preparation









Preparation



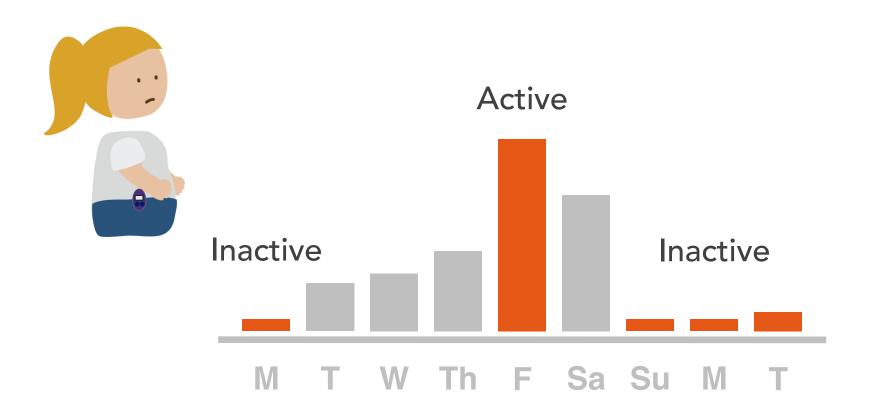
Preparation



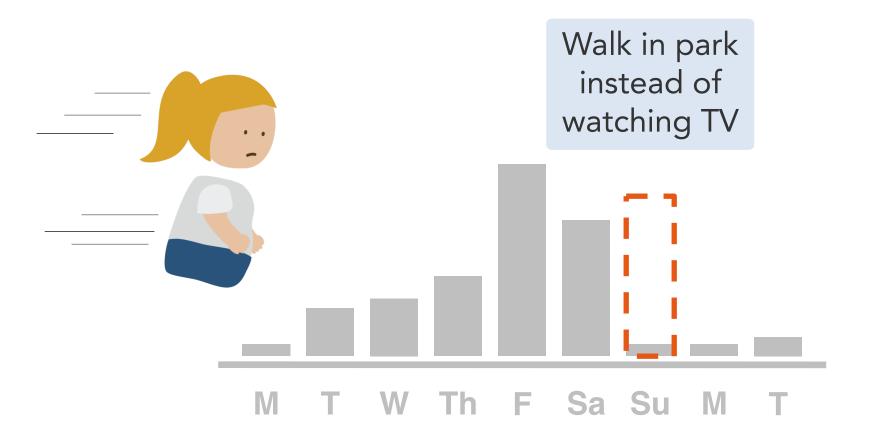
Integration



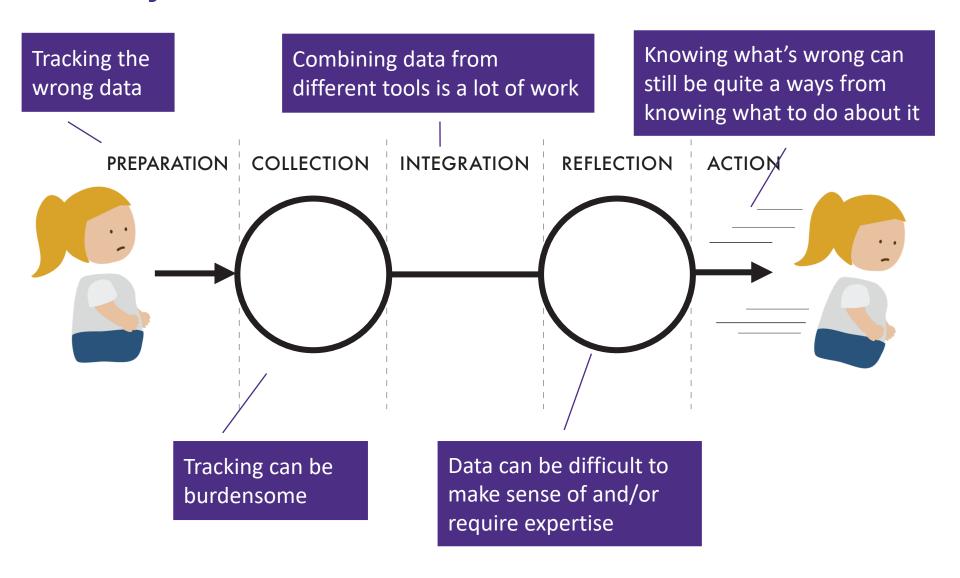
Reflection



Action



Reality is often far from the ideal



Can we design tools that reduce the burden of tracking and that help people enlist the help of others in tracking?



two contexts

Healthy Eating

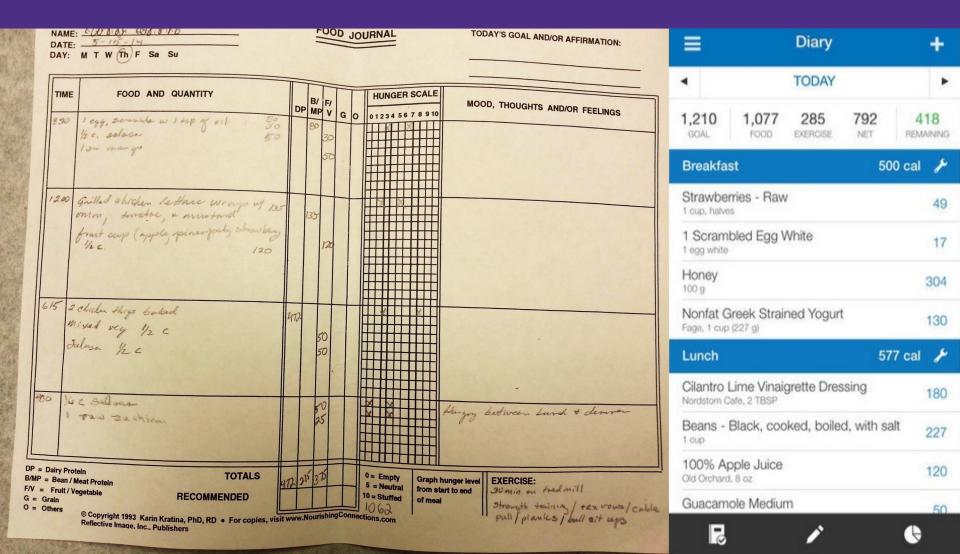
- Weight management, chronic disorders, and preventive care
- Goal: identify strategies for achieving desired outcome
- Track food, exercises, mood, stress, sleep

Irritable Bowel Syndrome

- Episodic abdominal pain associated with diarrhea and/or constipation
- Affects 20% of US population
- Goal: identify individualized triggers and manage symptoms
- Track food, symptoms



Food journals can help people monitor what they eat and tune their behavior.



Food journals can help people monitor what they eat and tune their behavior.



High burden to keep



Often feel judgy



Nudge people to exactly the wrong foods



Summaries & designs assume certain goals



Not designed to support collaboration



Risk of a data fetish



People will lapse. Design for it.



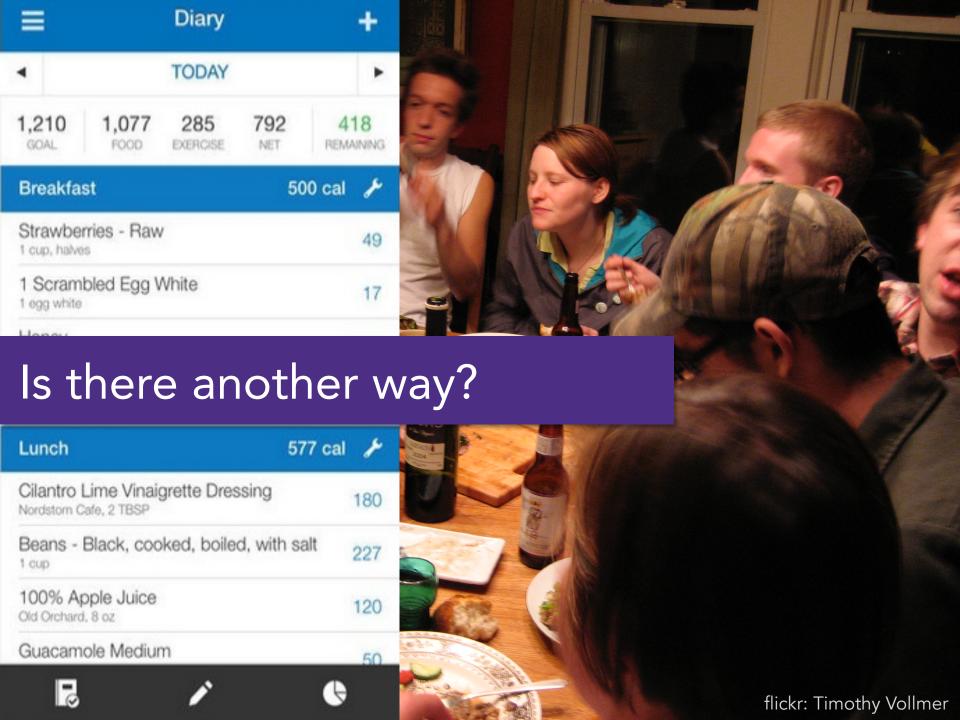
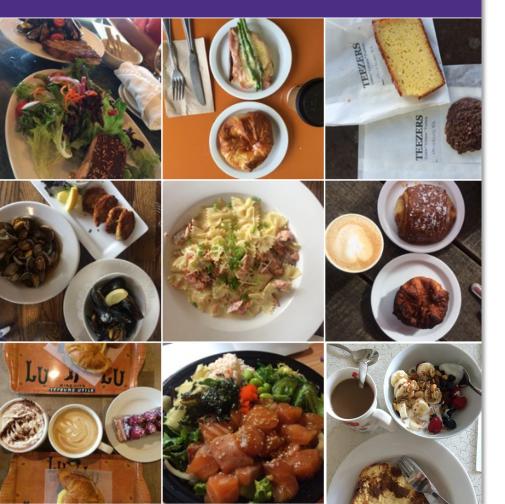


Photo-based food journals



Lower burden than traditional food journals.

More socially acceptable.

Capture more context.

Avoid many of the "negative nudges."

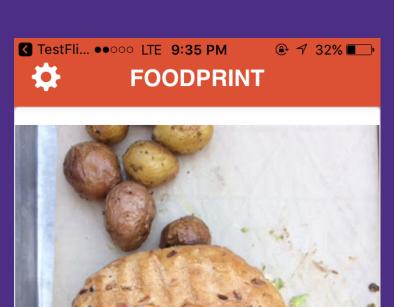
Mamykina et al. 2008; Cordeiro et al. 2015

Some people already use Instagram this way



Creates opportunity for accountability to followers.

Creates ability to learn by following others.



Vege panini 13:27 9/10, Sunday

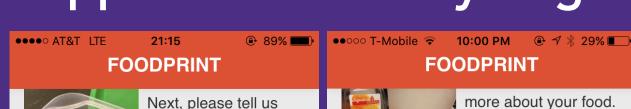






FoodPrint: A mobile, photo-based food journal, designed for flexible goals and collaboration.

support for a variety of goals





Next, please tell us more about your food.

Are there other things you would like to say about this food or meal?

(Optional)

How much sugar was in your food?

A lot

Some

e.g., What was the occasion? ...

None

I don't know

Does the food belong to the same meal as the previous photo? (Required)



s No

Are there other things you would like to say about this food or meal? (Optional)

e.g., What was the occasion? ...

Are there other things you would like to say about this food or meal? (Optional)

e.g., What was the occasion? ...

What was in your foods?

Grains Protein Oils

Vegetables Fruits Dairy

N/A

+ Add additional info about your food

How did you feel when you eat the food?







How stressed were you?





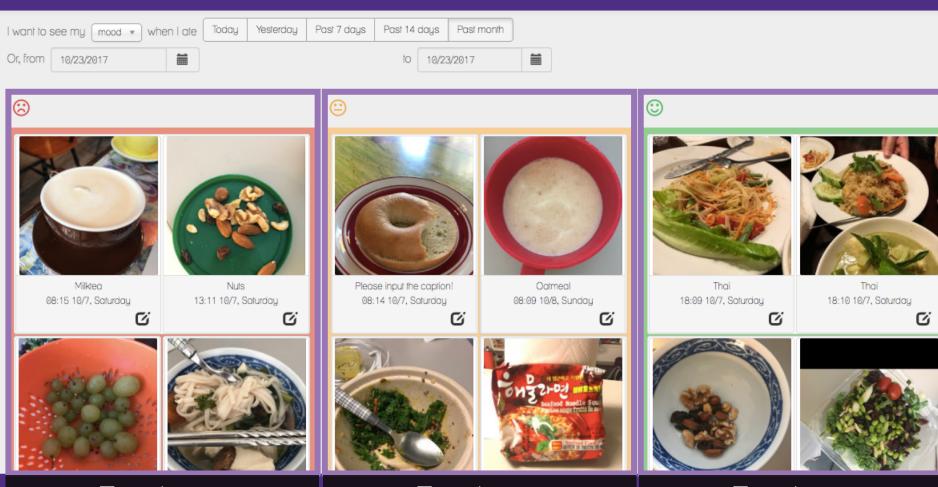


Balanced Diet

Ingredient monitoring

Stress & mood

web app supports review by goal



Food eaten in a bad mood

Food eaten in an okay mood

Food eaten in a good mood

Pre-visit notes Encourage explicit communication about goals

Goal

1. Goal of the visits

I would like to get a sense of my overall diet and whether it is sufficient and healthy. I also wanted to discuss ways to manage over-snacking and stress eating.

Summary

2. Summaries to the doctor or dietitian

(a) Have you found any patterns about your eating?

I tend to overeat at night - sometimes I'll continue eating second portions or snacking after dinner even if I'm full. I tend to snack more when I am stressed and there is easy access to food. If I don't prepare food ahead of time, I am likely to go to things that are less healthy. Sometimes, I felt my stress level was different than how I felt while eating the food.

- (b) Write down three or more major things you found in your data
 - a. I usually eat 2 or 3 times more than what I take the picture of (and sometimes snack on the meal as I prepare it, without taking accurate pictures of quantity)
 - b. I was more conscious of what I was going to eat when I started taking pictures, and I became better at waiting until I was genuinely hungry to eat
 - c. Eating with other people seemed to improve my mood.

Questions

3. Questions to the doctor or dietitian

Write down three questions or more you would like to ask your doctors or dietitians

- a. What are ways to control over-snacking when I get home?
- b. Are there certain categories of food I'm missing? Or are there times of day I should eat certain categories of food?
- c. What are generally good tips to maintaing a heahtly diet?

Onboarding
Interview
installation

Data collection
30 days

Exit interview
Individual interview
Collaborative interview

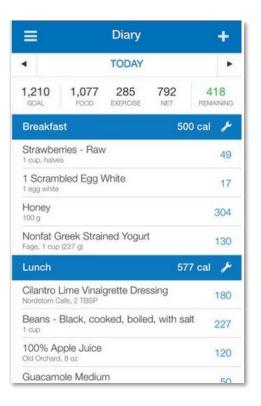
17 Patients

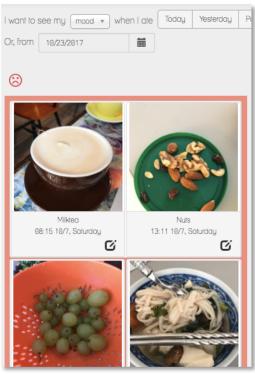
- 13 females and 4 males
- Goals included: balanced meal, ingredient monitoring, stress/mood

7 Providers

4 dietitians, 2 nutritionists, 1 health coach

Photo-based visualizations provided more details about eating habits





You get more information of what their meals look like.

It's interesting to have the information of how were they feeling when they ate it, how did they prepare it? I think that, to me, is more useful than how many calories or grams of fat were in something.

Dietitian

Pre-visit notes kept the focus on patient goals during collaborative review

Because I could see her goals and so I had an idea of what I was going to talk about. And fit the session within the timeframe that we had. It's nice to be able to see what the client wants to go over, and things that you're gonna plan on talking with the client on.

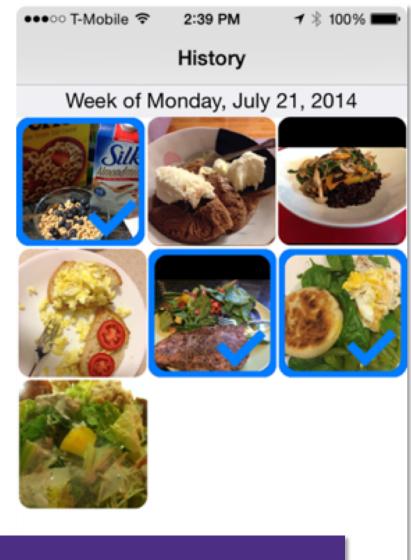
Dietitian

Numbers are alluring, but they are also reductionist.

Apps should assess people's goals and configure tracking accordingly.

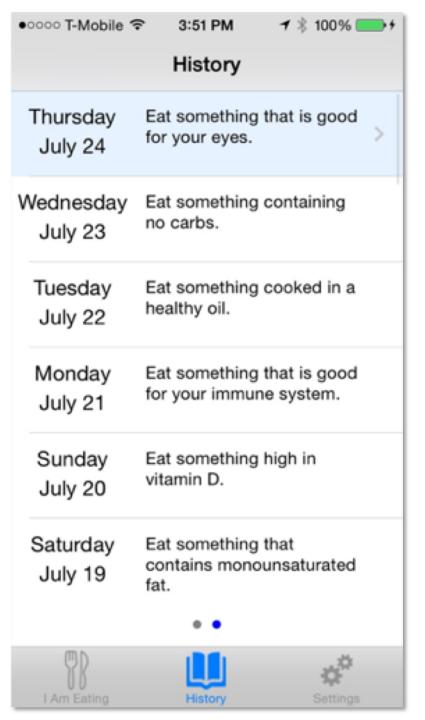
Design to give patients a space to react to their data and plan for their visit.

Can we further lower barriers and still deliver benefits?



Food4Thought





Four Versions







Nutrition challenges





Nutrition challenges

Nutritionally prescriptive, serious, conventional

- Eat something high in fiber
- Eat something with at least 20 grams of protein
- Eat something that is good for your eyes



Non-nutrition challenges

fun, curiosity inspiring, random, varied

- Eat something that is yellow
- Eat something that an elephant would eat
- Eat something that reminds you of your high school years







Nutrition challenges

- Higher engagement
- More judgy



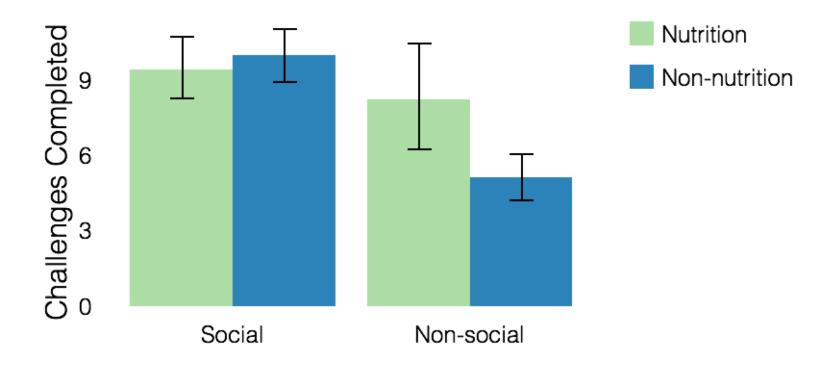
Non-nutrition challenges

- Greater gains in food mindfulness
- Challenges and activity felt more arbitrary



Social features

- Completed more challenges
- Less likely to use the app to record other foods



"Minimum viable data"

Design for experiences, not just data.





Severe Symptoms

Missing Work

Needs Help

Preparation

Collection

Integration

Reflection

Action

Jane



unsure what to do

Consults Brother

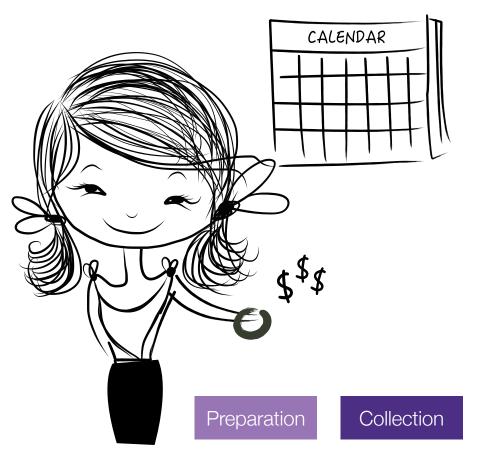
Had Similar Symptoms

Shares his Triggers

Stress & Exercise

Integration

Reflection



tracks stress & physical activity

Buys a Fitness Band

Tracks Mood

Tracks Physical Activity

Reflection



(tries to) make sense of the data

Lots of Data

Mood Over Time

Activity Over Time

But No Understanding

Integration

Reflection



maybe her doctor can help?

Did not track symptoms

Did not track food

Elimination diet

Difficult to follow

Difficult to interpret

Lengthy process

Possibly inconclusive

Integration

Reflection

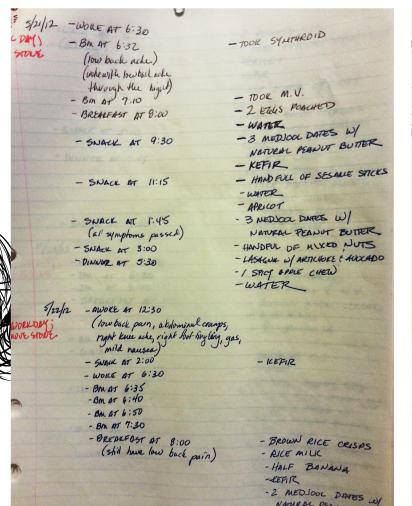
Collection Preparation

alternative: paper diaries

Tracks foods and symptoms on paper.

Plan to review together in a month.

Integration Reflection



Food/GI Symptoms Record Instructions: Please record everything you eat and drink (including ice and water taken with your medications). Circle your symptoms if any as they occur after meals and snacks Date: 6/2 2 Food & Beverages and Amount Symptoms if any (circle). Breakfast Time: Vomiting 1')4 e out meal w/2True rack Heartburn Stomach Pain CA Portebred-114+ sugar Constipation 1/2 Tr. Toes wheat free waffle Urgency Gas Sense of Bloating Cramping 1002. Peppermint +ea water, ted herore breakfast Other: Snack Time: 11:00 - 1-5lice french toast eg white, milk Lunch Time: 12:30 3 02 fresh cold broiled salmen Vomiting Nausea Heartburn Stomach Pain Lutein-402 Carberry Juce Diarrhea Constipation cater Floor totally feese avacado, ollvos caterom con lourat dressing marin rice IT. Cateros in a free interesting from the control of the co Sense of Urgency Gas Bloating Cramping Other: Dinner Time: 6:00 1C. chicken broth IT. rice Nausea Vomiting trafer, tea 402 organic braied chicken breast Heartburn Stomach Pain Diarrhea Constipation Baked Sweet yam, Steamed carrots, Sense of Urgency Gas Zucinni, cranberni sauce, tea, rasphern Bloating - afterdance Cramping Snack Time: 8.30 crackers, reduced sugar Jam Date: 6/25 Food & Beverages and Amount Symptoms if any (circle). 11/40 ratineal a Trice cereal. Nausea Vomiting 9:30 Heartburn Stomach Pain 3Trice milk-CA enriched-TraderJs unter suheat free wastle, maples grap It.
Snack Time 11:00 14e Sou Yogurt for blueberries mashed strauberries (yellow) crocker water Diarrhea Constipation Sense of Urgency Gas Bloating Cramping Other: Lunch Time: 1:00 Toust- 302 Roast Turkey Breast Nausea Vomiting Lutein water 14 adacado, mustard, romaine Heartburn Stomach Pain nardboiled eggwhite, spaked potato Diarrhea Constipation Chips-ted, zozeranbjuke Sense of Urgency Gas chew Bloating Snack Time: 400 pretzels, 1/2t peanot butter crackers
Dinner Time: 6:30 [-]00r tortila-402 Tilipa pan Cramping Other: multività scared, lemon, oliveoil, couscous Nausea Heartburn Stomach Pain Israeli, queen beans fresh, carrots + peas, apple sauce 1/4eup, blipbernes Diarrhea Constipation Sense of Urgency Gas water 1/29 inger cookie Snack Time: - raspherry sorbet, small piece y e (bureake (I baked) Cramping Bedtime-water Gooms gabapentin-every night align probiotic - 4-6 to times aweek after winch

Preparation

BM AT 10:45

Collection

Integration

NAMEDE PERNUT BUTE

Reflection



review of paper diaries

Inconsistent recommendations from provider to provider.

Bias in provider recommendations

Patients and providers leave frustrated.

Integration

Reflection

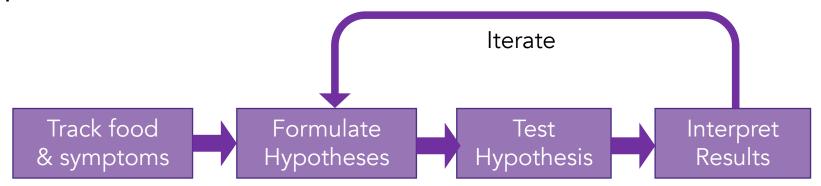
Action

C Chung, K Dew, A Cole, J Zia, J Fogarty, JA Kientz, SA Munson. *CSCW 2017.*Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data.

J Zia, C Chung, K Xu, Y Dong, JM Schenk, K Cain, SA Munson, MM Heitkemper. J Clinical Medicine. Inter-Rater Reliability of Provider Interpretations of Irritable Bowel Syndrome Food and Symptom Journals

recasting self-tracking

- Hypothesis formation based on journals
- Rethinking trigger detection to rigorously test hypotheses while reducing patient and provider burden.



recasting self-tracking

- Hypothesis formation based on journals
- Rethinking trigger detection to rigorously test hypotheses while reducing patient and provider burden

new analysis tools

BEFORE YOUR NEXT MEAL/SNACK & BEFORE BEDTIME:

Circle the number that best describes how severe each **symptom** was since you last ate or drank anything:

Did it last > 1 hour?

Abdominal Pain	0	1	2	3	Y/N
Bloating	0	1	2	3	Y/N
Constipation	0	1	2	3	Y/N
Diarrhea	0	1	2	3	Y/N

Circle the number that best describes how severe your **stress level** was since you last ate or drank anything:

Stress 0 1 2 3

 $\frac{\text{SYMPTOM KEY}}{\text{O} = \text{not present}}$

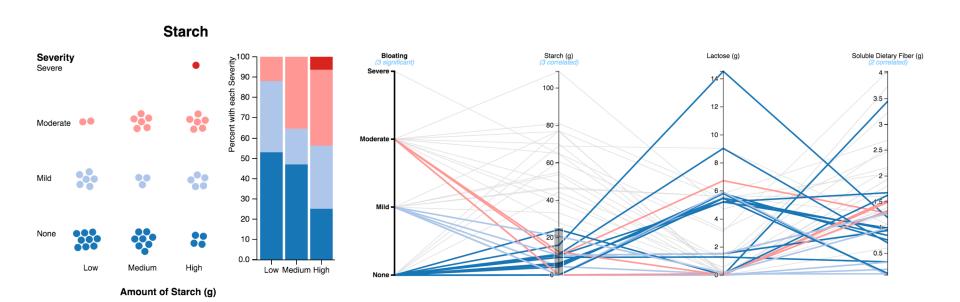
1 = mild

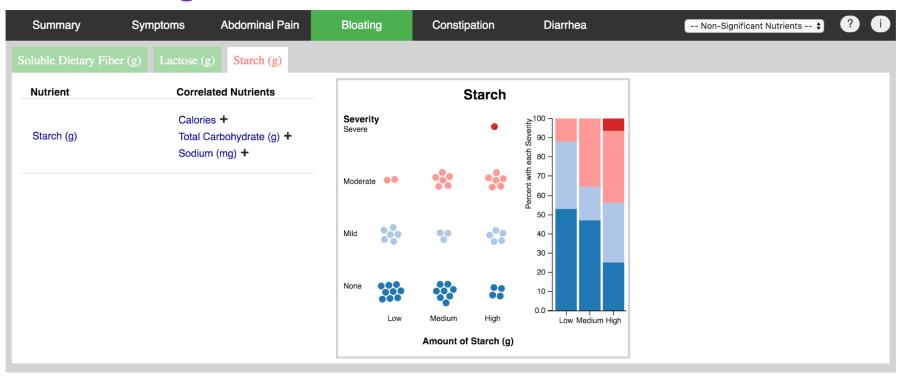
2 = moderate 3 = severe

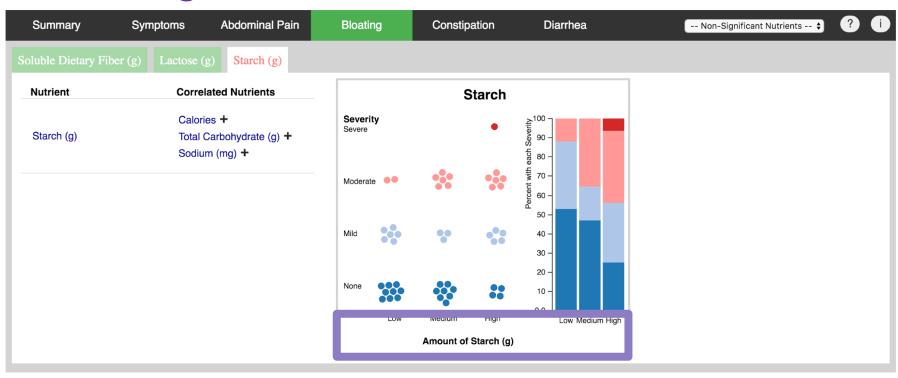
Food Item	Brand Name or Type	Fat or Salt Added	How prepared	Portio Size

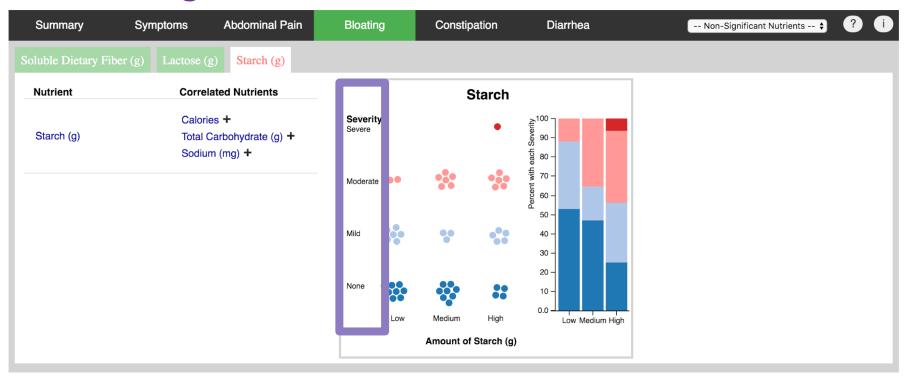
Time of Logged Symptoms	Lactose (g)	Total Dietary Fiber (g)
▼ 7/18/14 12:23PM	4.62	0.03
frozen strawberries (1 cup)	0.00	0.02
ice cream (0.25 cups)	4.62	0.01
▼ 7/18/14 1:30PM	3.63	0.50
cheese pizza (3 slices)	3.63	0.50
▼ 7/18/14 5:00PM	2.53	3.31
roasted cashews (0.5 cup)	0.00	2.02
milk chocolate (0.25 bar)	2.53	1.33
▼ 7/18/14 10:30PM	1.30	7.17
baked potato (1 potato)	0.00	6.77
shredded cheese (0.25 cups)	1.30	0.10
ketchup (1 tbs)	0.00	0.30
▼ 7/19/14 12:23PM	0.02	13.16
donut (1)	0.02	13.16

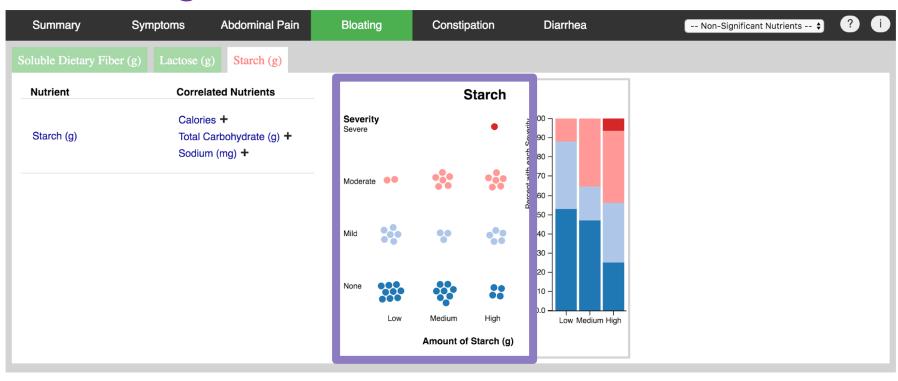
visualizing results



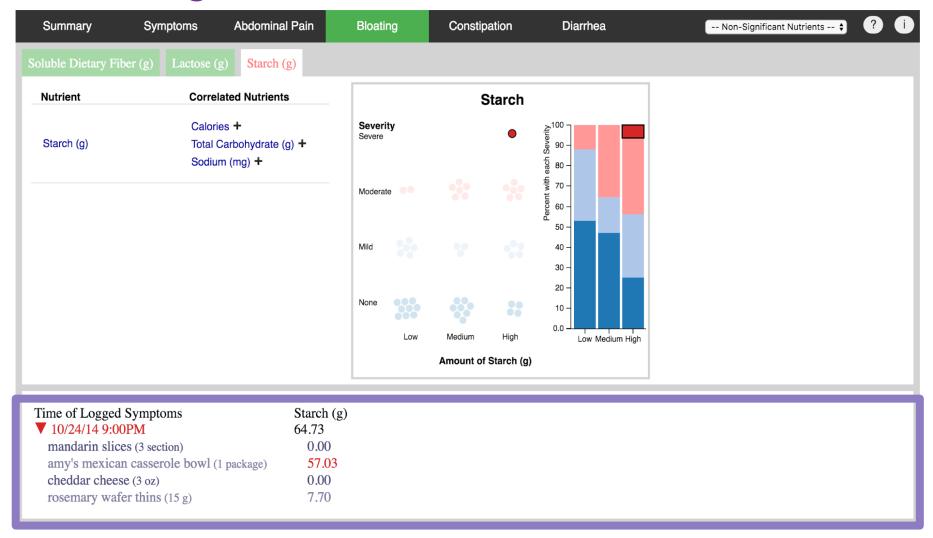




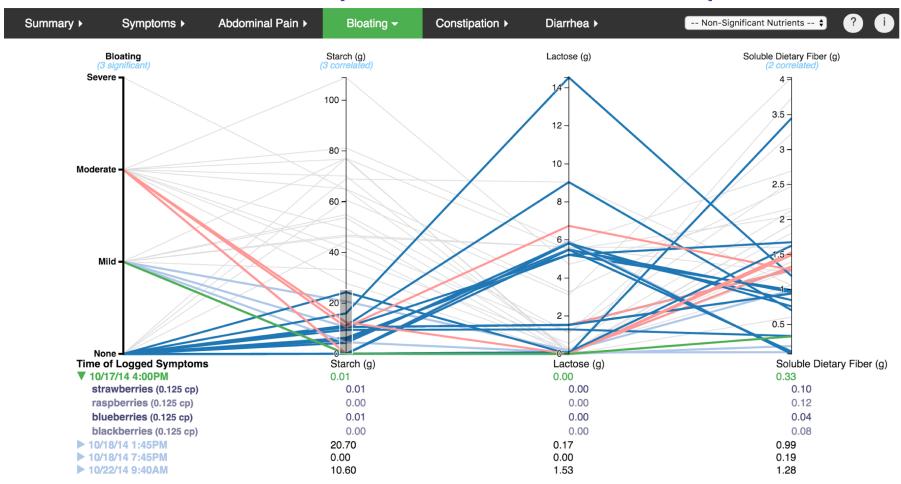








visualizing results: parallel coordinates plot



visualizing results: parallel coordinates plot



visualizing results: parallel coordinates plot

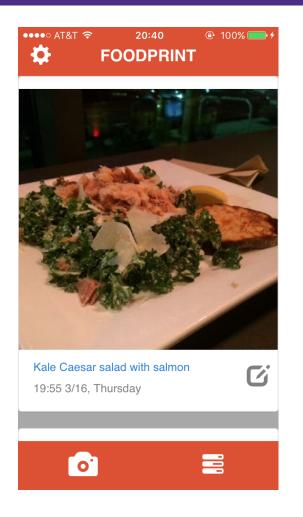


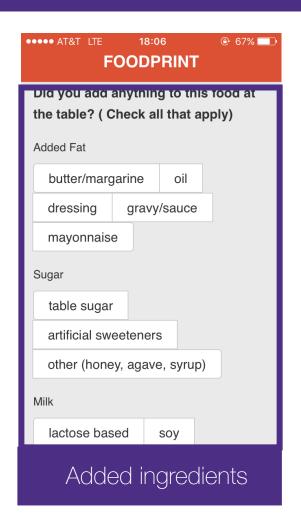
visualizations facilitated collaboration

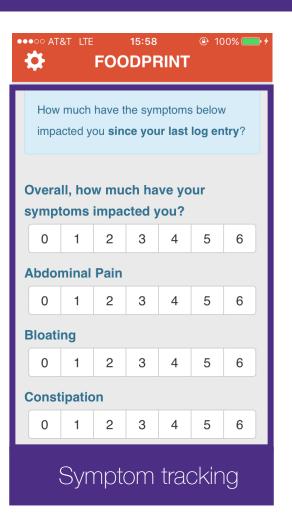
- Greatly preferred over analyzing paper diaries; reduced burden of synthesis.
- At least initially, patients and providers had concerns about data and results, but these were generally resolved through collaboration.
- Very different preferences for *how* to use these tools.

Can photos help in IBS too?

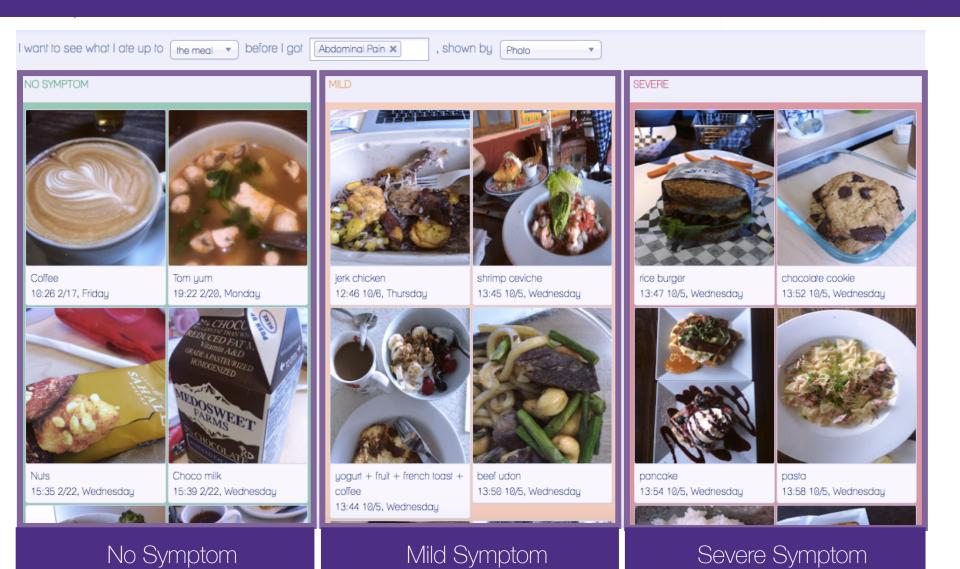
IBS Mobile app Supports low-burden food and symptom data tracking



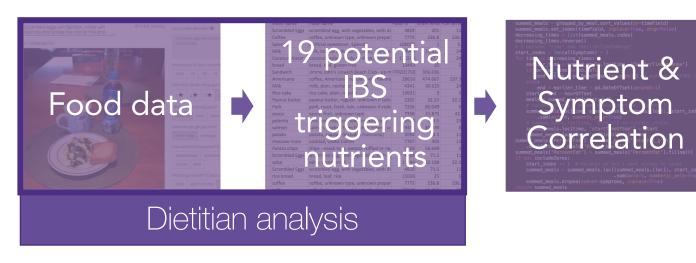




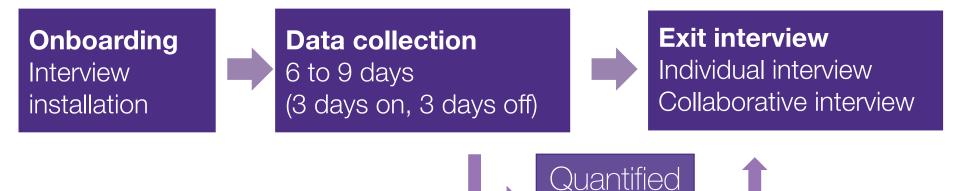
IBS Web app Provides tailored summary for review



Quantified analysis For half of participants







IBS study

16 Patients13 females and 3 males

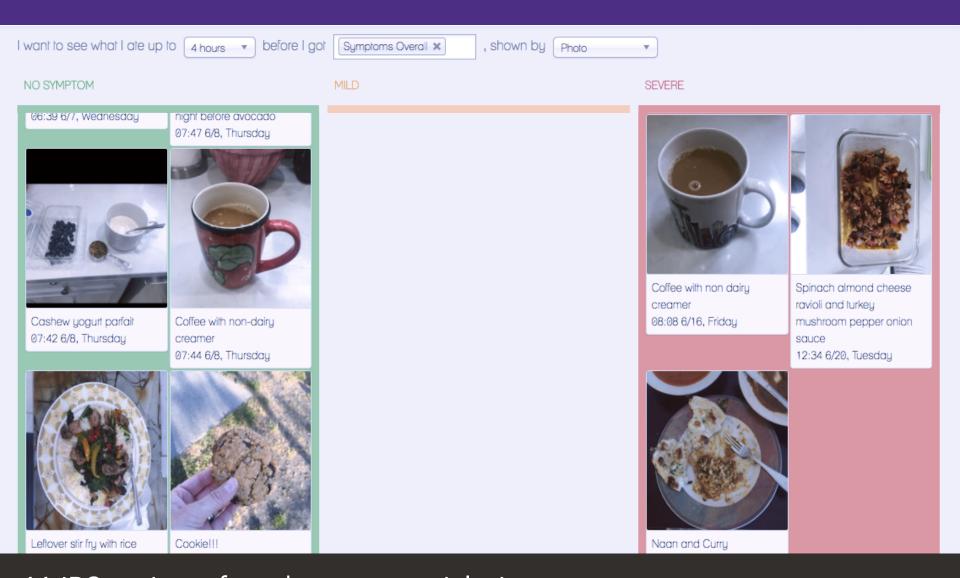
8 Providers

analysis

4 physicians, 2 nurses,

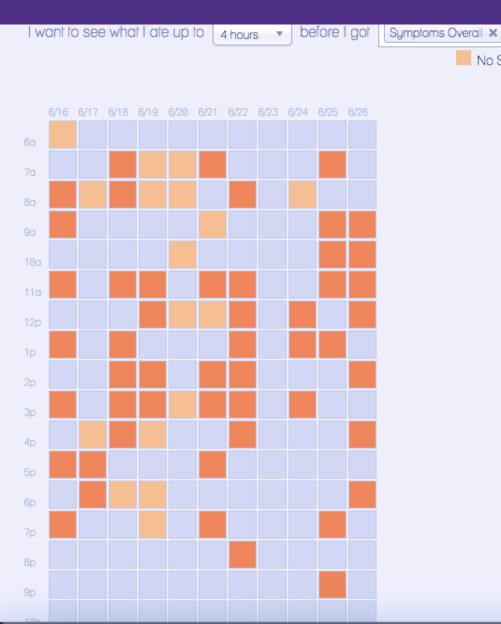
2 dietitians

Photo-based visualizations made it easy to see patterns



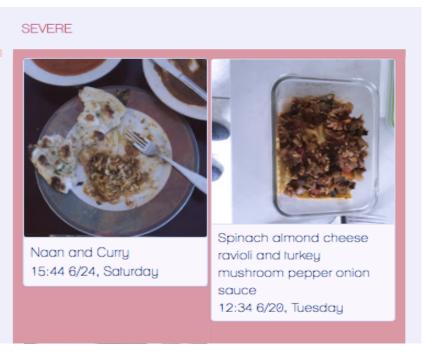
11 IBS patients found new potential triggers, 5 supported existing hypotheses

Photo-based visualizations made it easy to see patterns ... even to identify non-food triggers



No Symptom Mild Symptom Severe Symptom Show earlier time

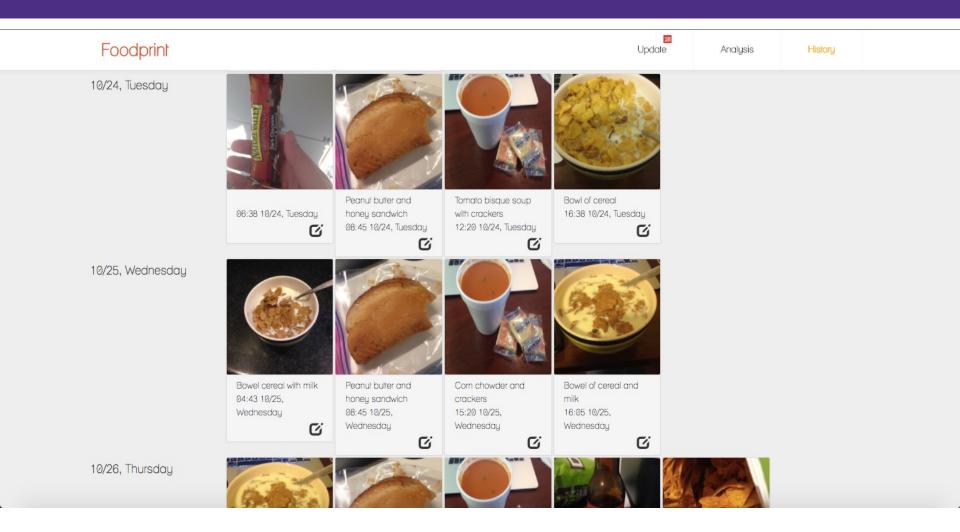
Pre-visit notes helped focus on patient goals during collaborative review



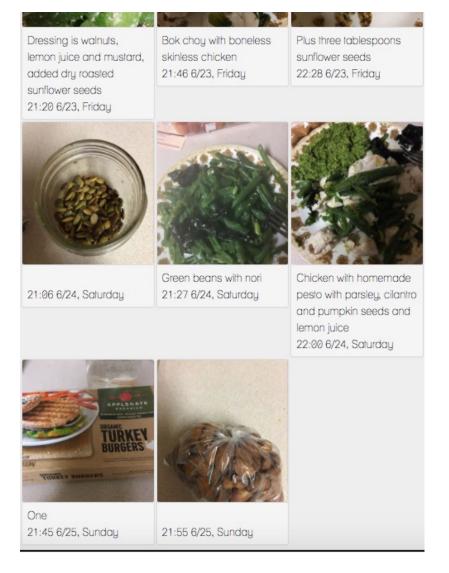
What we found to keep the flavor is to use the green tops of the scallions to cook in for the onion, and then you can use olive oil that infuse garlic. Or use one Indian spice, asafetida. It's very smelly but it tastes like garlic when you cook with it.

Dietitian 1 & IBS Patient 2

Shared visualization of real foods helped collaborative interpretation and knowledge exchange



Shared visualization of real foods helped collaborative interpretation and knowledge exchange



When you soak them [nuts], it helps leach out some of those FODMAPs.

We see that with tofu, too. Firm tofu is low FODMAP because they've kind of drained all that liquid out of there. And the FODMAPs and fermentable carbs tend to leach out with that. Whereas silken tofu, they blend that liquid in there so there's more FODMAP content in there.

Dietitian 2 and IBS Patient 3





Overview

Straightforward pattern

Food-symptom relationship

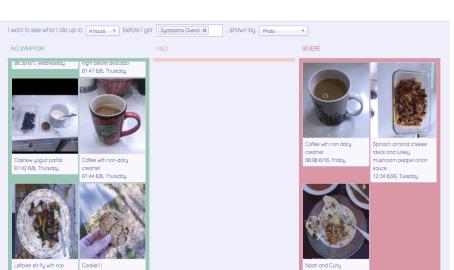
Supports conversation

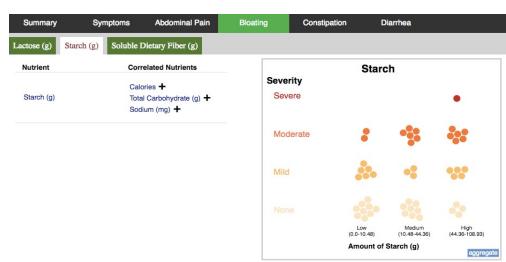
In-depth analysis

Underlying cause

Nutrient-symptom relationship

Requires provider knowledge





Context matters here, too

I want to see what I ate up to 4 hours v before I got



Banana

08:17 7/18, Tuesday

Symptoms Overall X

, shown by Photo

NO SYMPTOM



Coffee with lactose free milk. 30 oz container. 07:57 7/18, Tuesday



11:12 7/18, Tuesday

Carrots and tomatoes 10:11 7/18, Tuesday

MILD



Grilled pork chops with spinach salad with blue cheese, almonds, dried cherries and white vinegarette dressing 19:16 7/18, Tuesday



Coffee with lactose free milk. Drank 3/4 of a 30 oz container. 08:55 7/19, Wednesday



SEVERE



PB Sandwich 11:53 8/3, Thursday

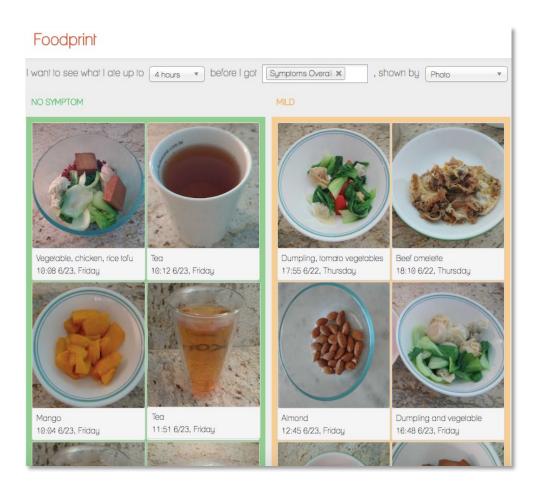


Coffee with lactose free milk 08:38 8/4, Friday



Vanilla yogurt with granola 08:47 8/4, Friday

Prior photos help people develop actionable plans

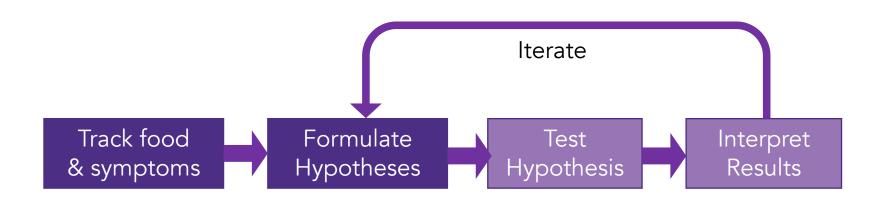


Is the kind of work that you do, do you have control over your day, so that you could actually every two hours step out and do something or are you at a kind of job where you can take breaks at specified times?

Nurse 5 and IBS Patient 7

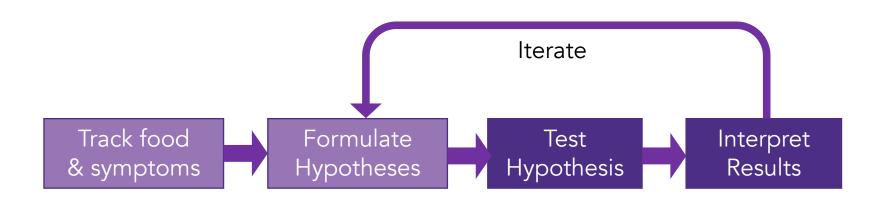
recasting self-tracking

- Hypothesis formation based on journals
- Rethinking trigger detection to rigorously test hypotheses while reducing patient and provider burden.



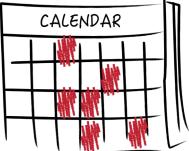
recasting self-tracking

- Hypothesis formation based on journals
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a new process for Jane





Severe Symptoms

Missing Work

Needs Help

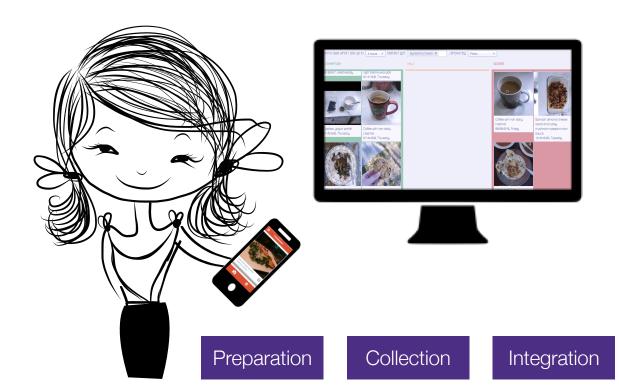
Collection

Integration

Reflection

Action

Hypothesis formation



Reflection

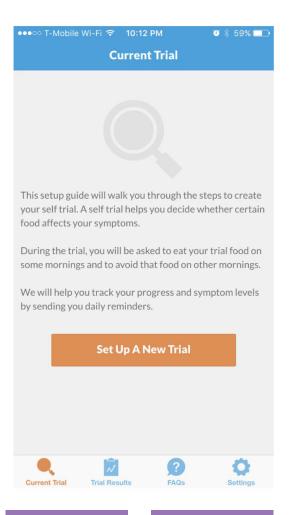
Action

Jane's personal hypotheses



designing a self-experiment





Collection

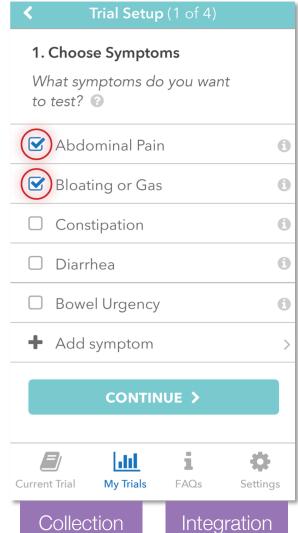
Integration

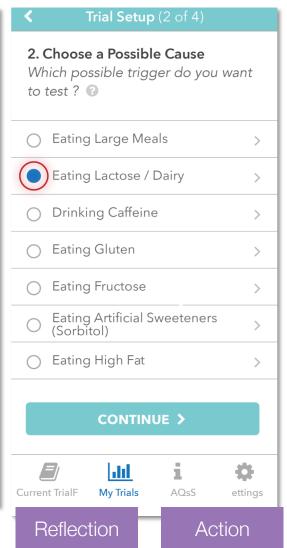
Reflection

Action

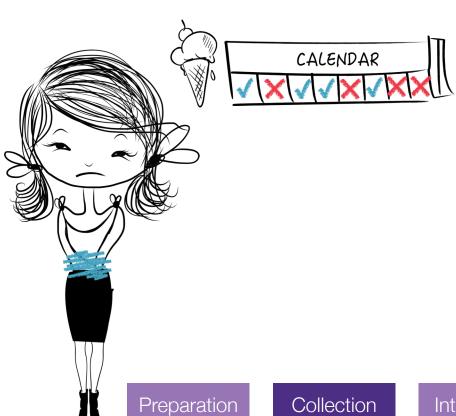
designing a self-experiment

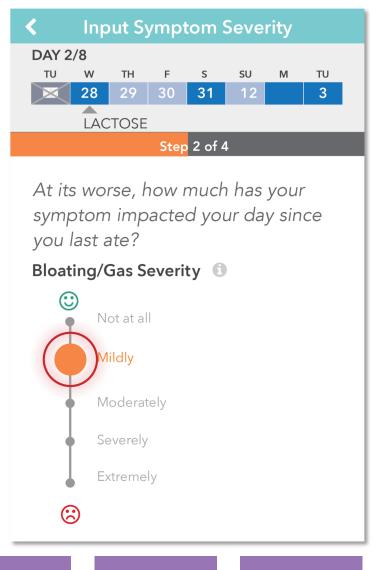






conducting the self-experiment



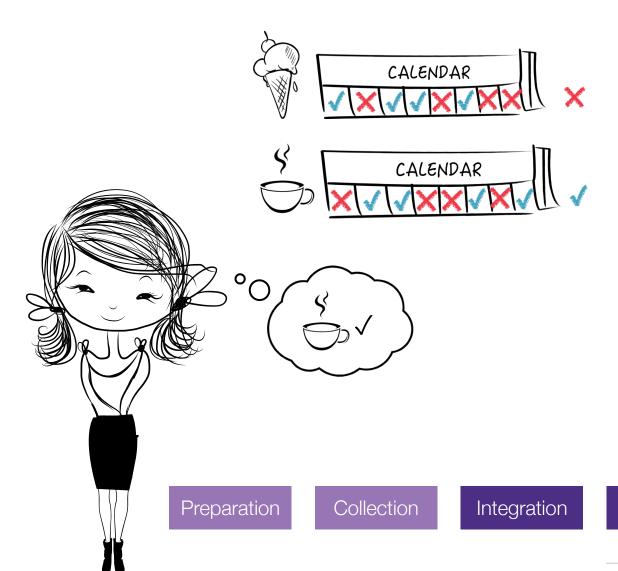


Integration

Reflection

Action

interpreting results





Eating Caffeine Study Findings

May 27th – June 3rd

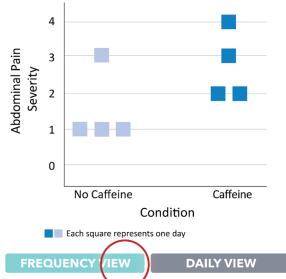
Abdominal Pain



Based on the study, there is a **no evidence** that your abdominal pain decreases when you don't eat caffeine (p=0.762). ②

Abdominal Pain Severity

May 27th – June 3rd



Action Reflection

Days without Caffeine was 1.5







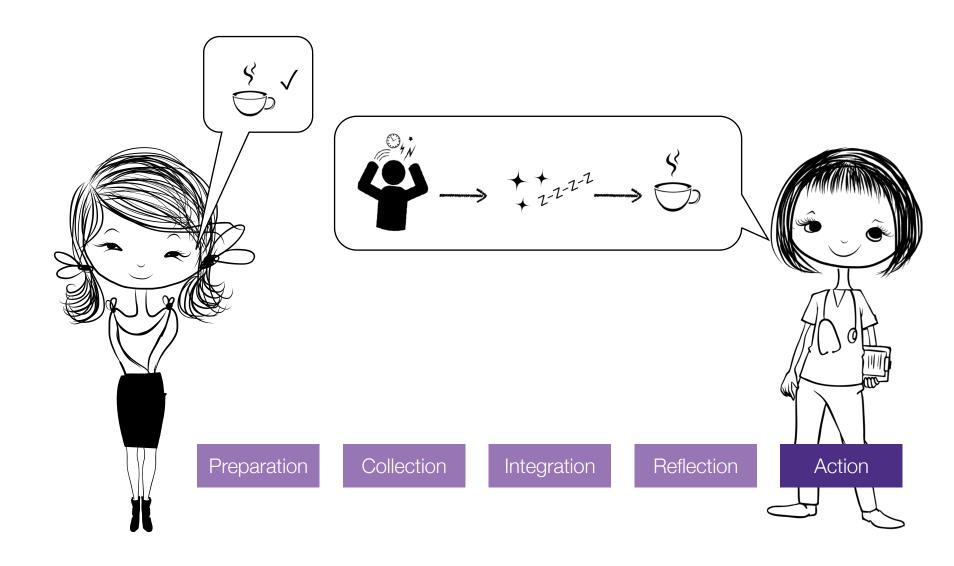






Past Studies Study Setup

actionable answers



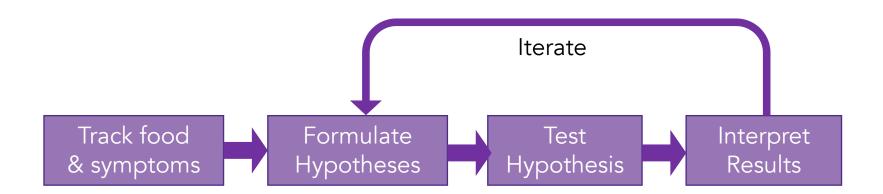
evaluation (15 person field study)

- High completion rate, low reported burden
- People:
 - Valued design of controlled experiment
 - Relied on visual analysis much more than statistical analysis
- Rigor: participants were willing to accept and act on less than scientific standards, to better fit study into their lives.



recasting self-tracking

- Hypothesis formation based on journals
- Rethinking trigger detection to rigorously test hypotheses while reducing patient and provider burden.



Patient generated health data will transform care.

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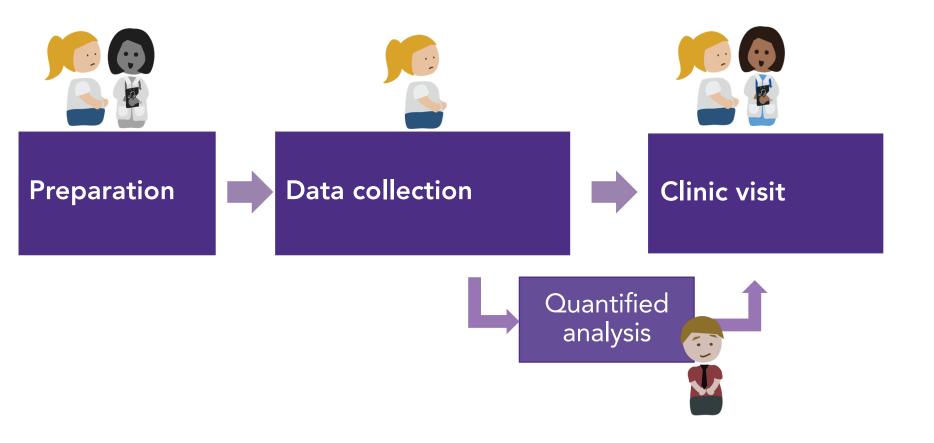
To succeed, designers need to:

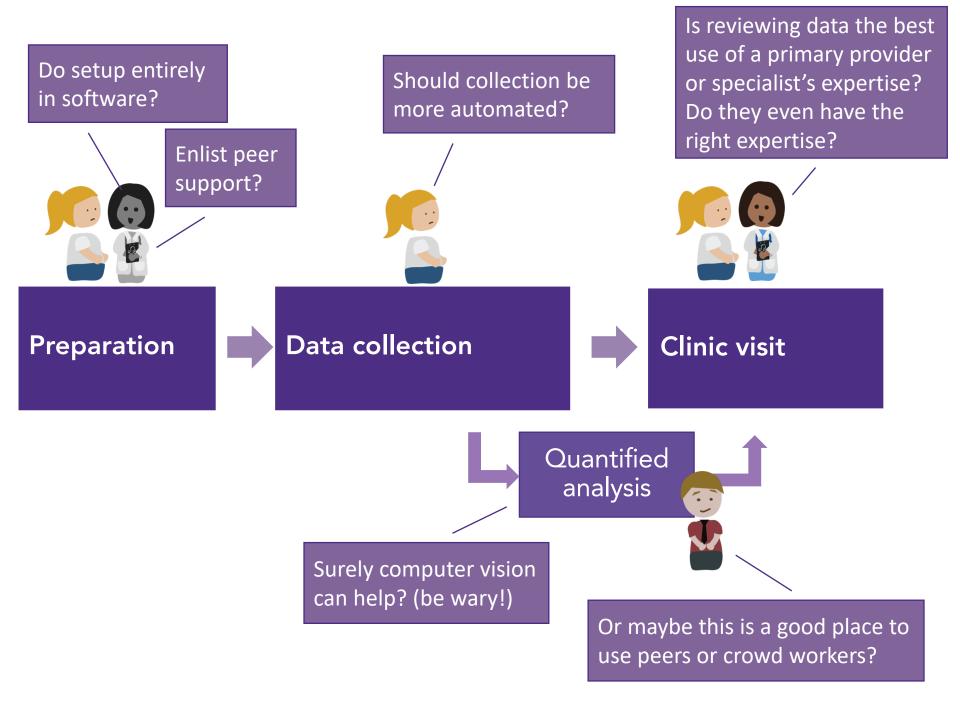
- Think beyond presenting numbers.
- Find new ways to understand and support people's goals.
- Design for collaboration from the start.

- Think autonomy and informed decision making, not adherence.
- Scaffold the entire process of tracking, from preparing to action, not just focus on improving collection.

There are some big challenges ahead.

Who should do what work?





How do we rearrange work?

standard flow for primary care visit





Fill out questionnaire



Weight, height blood pressure



Roomed, ready for visit











standard flow for primary care visit













revised flow















- Freed up medical assistant time to follow up with patients by phone.
- Some indications patients were more engaged with BP.

- Generally high perceptions of accuracy, some skepticism.
- Some patient privacy concerns.

C Chung, SA Munson, MJ Thompson, L Baldwin, J Kaplan, R Cline, BB Green Journal of the American Board of Family Medicine. 2016.

From Personal Data to Personal Health: Tools to Reduce Burden & Improve Collaboration

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University of Washington Innovation Award
Intel Science and Technology Center for Pervasive Computing
Robert Wood Johnson Foundation





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Many collaborators, especially PhD students who lead the projects:



Christina Chung



Daniel Epstein



Jessica Schroeder



Ravi Karkar



Jane Hoffswell





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