Collaborative Healthcare Using Patient-Generated Data

Mobile Apps for Generating and Sharing Food-Related Data

by the University of Washington

Produced by Reos Partners
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All the materials produced are available at the Reos Partners website:
www.reospartners.com/pgd

If you have other ideas for how to build on these use cases, please let us know:
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Acknowledgment
The use case methodology is adapted from *Writing Effective Use Cases*
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Contents

Technology has made it easy for people to capture data about their health, giving users insights that are more accurate and accessible than ever.

From counting steps to tracking fertility, people are drawn to using new tools to bring transparency and self-awareness to their well-being. Despite its promise, it is still unclear how to transform this wealth of self-generated data into meaningful improvements to the partnership between a patient and their healthcare provider. Proactive patients who wish to improve their personal health, as well as stakeholders from across the healthcare and health research field, are invested in finding ways to use patient-generated data (PGD, also known as PGHD or patient-generated health data) to inform healthcare and to transform it to be better, safer, more efficient, and more collaborative than before.

To provoke innovation within this emerging space, the Robert Wood Johnson Foundation engaged Reos Partners, an international social enterprise with experience in bringing collaborative innovation processes to life. Reos defined the scope of this inquiry through the question: **How might the use of patient-generated data enhance collaboration between patients and providers to improve individual health outcomes?** In two phases of work, Reos Partners investigated the opportunities and challenges facing thought leaders and researchers around this question. Reos Partners started with interviewing leaders and stakeholders from the healthcare field, including patients, healthcare providers, academics, technologists, designers, and representatives from public institutions. The outcome was a report that synthesized these conversations to capture insights, trends, and actions that could most directly improve health outcomes for patients.

With this research foundation, Reos Partners initiated a second phase of work by inviting four health innovation teams from across the United States to propose approaches that could use patient-generated data to make healthcare more collaborative. Over three months, these teams produced a series of scenarios that articulate how PGD could be used to improve the clinical encounter between a patient and their care team (a methodology known as "use case").

While the initial Reos Partners report identified a number of emerging challenges and opportunities in the PGD landscape, these four teams were asked to pursue research advancing one or more of the following focus areas:

Shift Toward Trust

Patient-generated data should be viewed as a trusted, valid, and reliable input to the clinical encounter that enables collaborative decision-making between patients and their care team.

> How might we increase clinicians' receptivity to using patient-generated data in the clinical encounter?
> How might we find the balance between clinically generated and patient-generated data?
> How might we establish rigor within the context of patient-generated data?

Identify Mechanisms for Meaningful Collaboration Between Patient and Provider

Patient health and well-being should be co-produced with providers through meaningful communication and collaboration.

> How might we translate and present large amounts of data into comprehensible and relevant information that can be used by patients and providers?
> How might we improve the quality of data-driven conversations between patients and their care team?
> How might we use patient-generated data to meaningfully incorporate patients' experiences into decisions about care and treatment plans?

Bring Patient Stories into the Clinical Encounter

The day-to-day lived experience of patients should be understood to be important and reliable data that can inform their healthcare options.

> How might we track behaviors that promote wellness and well-being?
> How might we track and synthesize qualitative data that enables patients to tell their whole story?
> How can the burden of recording large amounts of data be reduced?

Each innovation proposed a unique approach to integrating patient-generated data, through several use cases that explore different perspectives and outcomes within the same topic (referred to as "use case suites"). By publishing these use case suites, along with a how-to guide to create your own use case, we aim to inform the future of using patient-generated data to make healthcare more collaborative.

Four research teams investigated various ways to co-produce improved health outcomes using patient-generated data.

Each team's use cases are outlined in a respective document and corresponding video overview, available at: www.reospartners.com/pgd

Four suites of use cases			

Research Team	Propeller Health	Northwestern University & Rush University Medical Center	RTI International & the University of North Carolina at Chapel Hill	University of Washington
Context	Using Patient-Generated Data Reports to Individualize Care for COPD	Integrating Wearable Device Data into Mental Health Care for Veterans	Standardizing and Evaluating Consumer Wearable Device Measurement	Mobile Apps for Generating and Sharing Food-Related Data
Number of Use Cases	2	4	3	3

Using Patient-Generated Data Reports to Individualize Care for COPD

by Propeller Health

Using an inhaler sensor that pairs with a smartphone app, researchers created a platform to collect and reflect data about inhaler usage from patients living with chronic obstructive pulmonary disease (COPD). For this use case suite, the patient-generated data is translated into reports to be used by patients to help self-manage their care as well as by physicians to help improve their methods for creating individualized treatment plans for their patients.

Standardizing and Evaluating Consumer Wearable Device Measurement

by RTI International & the University of North Carolina at Chapel Hill

By analyzing the broad use of wearable technology in health studies, researchers established an evidence-based protocol to evaluate the reliability and validity of these devices. This framework is designed to evolve and scale as patient-generated data technology expands and improves.

Integrating Wearable Device Data into Mental Health Care for Veterans

by Northwestern University & Rush University Medical Center

Researchers created recommendations for ways to integrate Fitbit devices into a mental health treatment program for veterans living with post-traumatic stress disorder (PTSD). This team speculates how providers might be trained to use patient-generated data to provide physiological insights that could be used as a point for reflection and conversation with patients.

Mobile Apps for Generating and Sharing Food-Related Data

by the University of Washington

To help patients identify opportunities for healthy change within their diet, researchers developed a suite of mobile phone applications that empower users to monitor symptoms and form hypotheses about what might be affecting them. Foodprint is a photo-based diary that patients can use to capture visual records of what they eat, as well as notes detailing ingredients and symptoms. TummyTrials is a mobile app that structures low-impact diet experiments that the user can explore on their own to better understand what elements of their diet might be triggering undesirable symptoms. These apps help the patient make more informed food choices and improve communication between the patient and their health provider.

What are use cases and why are we using them?

A use case is a story that tells the journey of a person as they work to achieve a specific goal within a defined scope or "system." Use cases, as a problem-finding methodology, were first created by software designers to discover what needed to be in place for the software user to engage with a program successfully. By starting with understanding users' needs and possible challenges as they attempt to navigate a system, designers could then create with this journey in mind as well as anticipate where things could go wrong.

For this initiative, we have taken the use case methodology and adapted it to explore the question:

"How might the use of patient-generated data enhance collaboration between patients and providers to improve individual health outcomes?"

If you are interested in knowing more about use case methodology, please see the appendix for an overview.

Fully Dressed Use Case Template

Team Name

Patient Generated Data Focus Area
☐ Shift Toward Trust
☐ Mechanisms for Meaningful Collaboration Between Patient and Provider
☐ Bring Patient Stories into the Clinical Encounter

Patient Generated Data Challenge
Tell us about the specific challenge your team is trying to address within the focus area you have identified

Use Case Name
The name should be the goal as a short action oriented statement

Design Scope
Describe the system within which the use case is taking place

Goal Level
Is this a summary or a user-centered goal?

Primary Actor
Who is trying to achieve a successful outcome within this use case?

Stakeholders & Interests
List all stakeholders and key interests that are impacted by this use case

Preconditions
What conditions need to exist for this use case to be relevant or actionable?

Triggers
What are the events or actions that start the use case?

Minimal Guarantees
What will be achieved in the course of the use case no matter what?

Success Guarantees
What are the outcomes if the use case goal is successful?

Mobile Apps for Generating and Sharing Food-Related Data

by the University of Washington
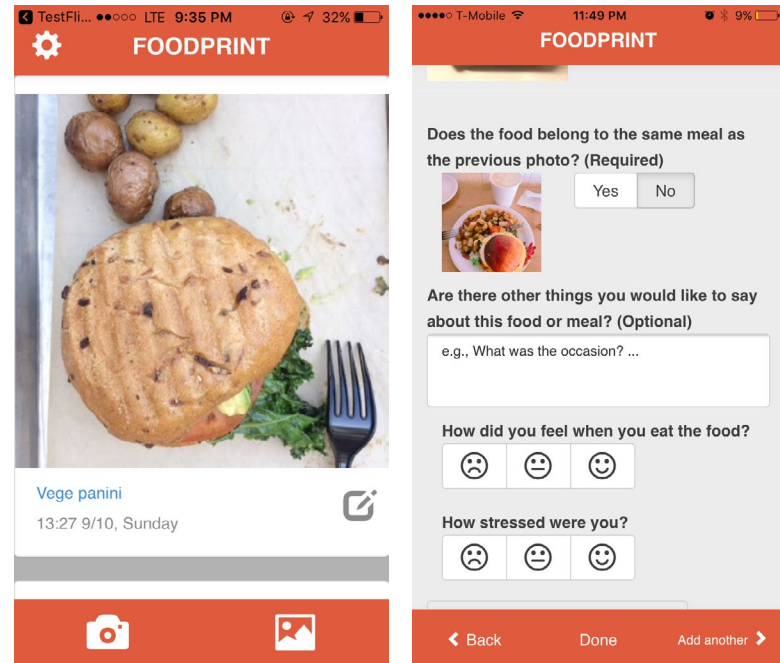
About This Use Case Suite

The relationship between the foods people eat and their daily health can be hard to isolate and understand. Not only is it difficult for people to record the contents of their meals—known as keeping a food diary—but it is also a challenge to form and test a diet hypothesis once an individual has an idea about what in their diet may be triggering their symptoms. The stakes for correctly recording eating habits and identifying patterns in symptoms is especially high for individuals who suffer from chronic gastrointestinal conditions, such as irritable bowel syndrome (IBS). Unfortunately, traditional calorie-based food diaries can be hard for patients to maintain and even harder for care providers to interpret on the spot in a clinical visit. As a result, providers and patients have little trust in this data and have difficulty providing timely, individual recommendations based on collected data.

Our team at the University of Washington set out to create a suite of mobile applications to bridge this gap between the foods people eat, the health outcomes they experience, and the ways patients collaborate with their healthcare providers to understand and manage their food choices. Foodprint is a mobile app that encourages users to keep a photo-based food diary that tracks what they eat over several consecutive days and then helps analyze that data to identify patterns, opportunities, and questions related to their health. Because identifying and acting on these insights often requires medical expertise, the tool is designed to be used in collaboration with the patient's healthcare providers—including their primary care providers, gastroenterologists, and dietitians—by creating rich, visual summaries of the patient's food diary. A second app, TummyTrials, can then guide patients on how to integrate low-impact experiments into their diet in order to tests these hypotheses.

Our suite of use cases explores scenarios aligned with three apps. The first use case is a version of the Foodprint app created specifically for patients living with IBS, who can use Foodprint collaboratively with their health provider to identify possible gastrointestinal triggers. The second use case is for a separate app, TummyTrials, that tests hypotheses for possible gastrointestinal triggers in IBS patients by facilitating which foods to eliminate and for how long. The app will then follow up, prompting the user to record any symptom changes they have

noticed and suggesting new foods to eliminate if the symptoms persist. The third use case is a broader version of the Foodprint app that helps any patient gain a general knowledge of their eating behaviors and make positive changes to their diet, not necessarily associated with any specific disorder or condition.

This suite of use cases demonstrates how the Foodprint and TummyTrials apps can provide insight into the relationship between a patient's diet and their health, empowering them to make dietary choices both individually and collaboratively with their physician.

About This Use Case Suite (continued)

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Use Cases in this Suite

**Summary
Use Cases x3**

1 Foodprint for Irritable Bowel Syndrome: Capturing and reviewing foods and symptoms to identify gastrointestinal triggers

2 TummyTrials: Rigorous and low-burden testing of potential food triggers

3 Foodprint for Healthy Eating: Capturing and reviewing foods to identify opportunities for healthy eating

Foodprint for Irritable Bowel Syndrome: Capturing and reviewing foods and symptoms to identify gastrointestinal triggers

Focus Area & Challenge

The specific patient-generated data challenge addressed

How can a lightweight photo-based food diary mobile application empower patients living with irritable bowel syndrome to manage their diets and experience reduced symptoms?

Scope

The system within which the use case is taking place

- Foodprint IBS supports patients living with irritable bowel syndrome as they work to understand the relationships between what, when, and how much they eat and their resulting symptoms. They can review the results on their own or in collaboration with their health provider.
- IBS is estimated to affect 10–20% of the US adult population; direct costs are estimated at $1.9 billion and indirect costs are estimated at $19.2 billion. [Source: *The burden of IBS: Looking at metrics*] While Foodprint is primarily designed for the IBS use case, it can be applied to a wide range of food-triggered gastrointestinal disorders.

● Primary Actor

The person/people trying to achieve a
successful outcome within this use case

Patient

- A person who has been diagnosed with
  IBS or who suspects that foods trigger
  or exacerbate their gastrointestinal
  symptoms.
- They want to experience reduced
  symptoms without over-constraining
  their diet (i.e., needlessly eliminating
  foods). They want to reduce their
  symptoms quickly, but they also want
  to get these answers with minimal
  disruption to their life.
- They are highly motivated because of
  the symptoms they regularly experience.

Health providers   Patient   Family/friends

Stakeholders & Interests

The stakeholders and key interests
that are impacted by this use case

Health providers (primary care physician, naturopath, or gastroenterologist)

- want to help the patient quickly and efficiently,
  bringing any medical/domain expertise to
  the problem
- want to make sure that providing care fits
  within their existing routines/workflows and
  billing structure
- may have concerns about whether they have
  sufficient expertise to advise on diet

Family/friends

- want to help patient experience reduced
  symptoms without having to cook too many
  "special" things or make too many compromises
  about where/what they eat
- may be skeptical about whether patient's
  condition is real

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Preconditions

The conditions that need to exist for this use case to be relevant or actionable

Patient

- Patient must believe that Foodprint will help them to achieve their health goals without disproportional cost or effort (or at least less cost and effort, or a greater probability of success than other tools they have tried).
- Patient must be able to see the whole arc of how they might use Foodprint over the coming weeks or months.
- Patient must have a smartphone compatible with the Foodprint IBS mobile app.
- Patient must be comfortable having their data stored online.

Health provider

- Provider must work within a regulatory environment that allows patients to share data.
- Provider must be open to reviewing patient-generated data and engaging in collaborative review.

Triggers

The events or actions that start the use case

- Patient develops a hunch or curiosity about possible relationships between their food and their symptoms and finds out about the Foodprint IBS app from peers or an internet search; or
- Health provider suggests the Foodprint IBS app to the patient when discussing gastrointestinal symptoms in a clinical visit.

Minimum Guarantees

What will be achieved in the course of the use case, no matter what

- Patient becomes more mindful of what they eat.
- Patient learns more about the relationships between the foods they eat and the symptoms they experience (even if they learn that these relationships are not strong or clear for them).

Success Guarantees

The outcomes if the use case goal is successful

- Patient becomes aware of the relationships between foods and the symptoms they cause, identifying both suspect foods that they can safely eat, trigger foods they can eat in modest quantities, and trigger foods they generally wish to avoid.
- Patient finds that knowledge of the potential consequences of eating particular foods makes them feel empowered about managing their diet. This is in contrast to diets developed from population-level knowledge that can often seem overly restrictive and not always relevant to any individual.
- The people with whom the patient regularly eats (family members, friends) also are more knowledgeable of the patient's dietary constraints.
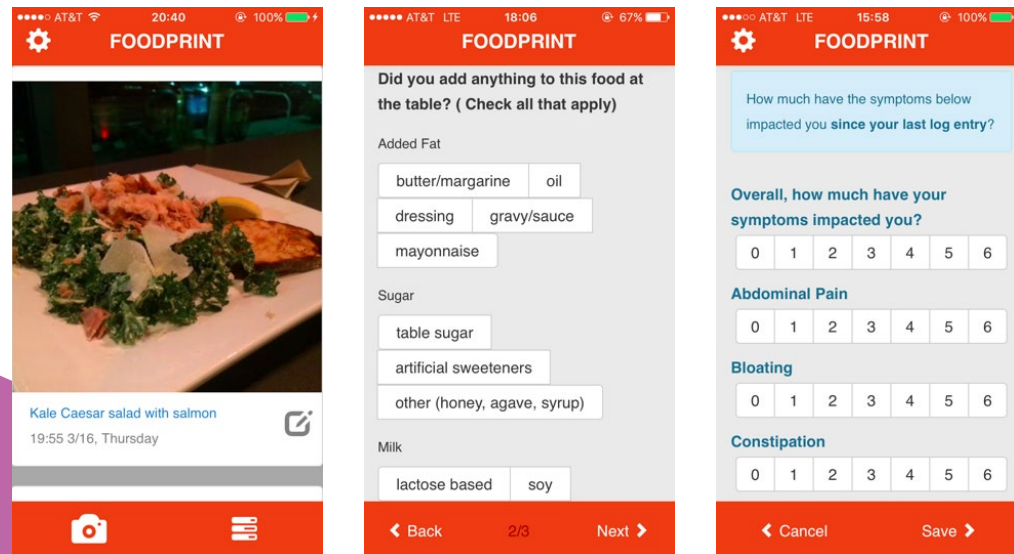
Success Scenario

The narrative sequence of events (steps) that lead from the preconditions and trigger to the completion of the goal by the primary actor

This suite of use cases includes three summary goals and no user goals. If further use cases were to be developed, then step 6 (Patient reviews the data) would be valuable to articulate in more detail as a user goal, as its success can have a cascading impact on the success of the subsequent steps.

"If…then…"

Crucial breakdowns in the main Success Scenario steps, and the way in which the breakdown will be handled

1

Patient downloads the Foodprint IBS application and registers an account.

If patients are not comfortable creating accounts and having their data stored online, **then** Foodprint may consider an offline version or educational materials about how information is stored.

2

Patient configures their tracking, including selecting default reminder times and which symptoms they wish to track.

If the app does not represent the symptoms that the patient wishes to track, **then** they can enter custom symptoms.

3

Patient tracks what they eat and symptoms they experience for at least two weeks (though possibly not every day—they may follow a plan of three days on, three days off).

If patient forgets to track what they eat or their symptoms, **then** they can reconsider their strategies for remembering to track. For example, they might adjust their app notifications to make sure the timing of reminders suits their lifestyle, or they might ask friends/family or work colleagues to help them remember.

(**If** the patient fails to track the foods they eat or the symptoms they experience, **then** the system does not work effectively.)

4

[Optional*] Patient can adjust their tracking based on initial data (for example, they see that they only experience varying and sometimes severe symptoms at/ after dinner, so they track only from dinner through bedtime).

If patient does not understand the visualizations well enough to make these inferences, **then** they can engage a health provider, a friend, or a family member who understands the visualizations.

5

[Optional*] A dietician (or, in the future, an automated system) codes the photos for constituent nutrients that are also likely triggers.

If the patient has not recorded enough detail in their food entries, **then** it may be impossible to complete the photo coding.

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Success Scenario

The narrative sequence of events (steps) that lead from the preconditions and trigger to the completion of the goal by the primary actor

"If…then…"

Crucial breakdowns in the main Success Scenario steps, and the way in which the breakdown will be handled

6

Patient reviews the data. They may form initial hypotheses based on what they see or they may look for evidence regarding hypotheses they had when they started using the application. They also may form questions that they wish to bring to their health provider or ask a peer. Based on the results, the patient may plan to adjust what they eat, how they prepare it, or how they eat it. This could include foods they are happy to discover they can eat or foods they continue to wish to avoid.

If the patient does not understand the grouping and visualization tools, **then** they can bring the data to their health provider or engage a friend/family member who understands the visualizations. They can also go back to step 5 if they skipped that optional step the first time and did not have their data coded by a dietician.

(Engaging these people requires that the patient have access to such people as resources. Future versions of the system could facilitate sharing the data on existing peer support forums or creating a peer community.)

7

[Optional*] Patient visits their health provider and they collaboratively review the data. The health provider offers additional perspectives and confirms whether, based on their medical expertise, certain hunches are plausible. The web visualization facilitates this conversation, but it is patient-focused and patient-directed. The patient and provider may plan to adjust what the patient eats, how they prepare it, or how they eat it. This could include foods they are happy to discover they can eat or foods they continue to wish to avoid.

If the health provider refuses to engage with the patient-generated data, **then** the patient can connect with peers or seek a new provider who is trained in the Foodprint system and how to review its data.

8

Based on the review (individual or collaborative), the patient enacts their plan for dietary or other changes. They may continue tracking while they do this, or they may choose to suspend tracking. Ideally, the system would also generate a report that the patient could use to help plan cooking and ingredients—alone or shared with family members.

If the results are inconclusive or not actionable, **then** the patient can continue tracking to collect more data. They can also go back to step 5 if they skipped that optional step the first time and did not have their data coded by a dietician.

If the results present evidence that a food/nutrient is a trigger, but the patient is reluctant to give up that food/nutrient, **then** they may choose to accept the negative consequences, knowing that Foodprint helped empower them to make an informed decision. Alternatively, if the patient wants to be more confident, they could shift to using another tool, TummyTrials (see Use Case 2).

*Optional steps require additional human and financial resources, so a patient might choose to skip these steps if they believe they are unnecessary, especially because these steps are more costly (their insurance company might want the patient to skip these steps).

[As needed/desired] If the behavior changes do not result in desired/expected symptom reduction, then the patient can resume tracking. Additionally, if their symptoms later flare up, they can also use Foodprint to identify possible causes. (In order to re-engage with the app, the patient must still have some confidence in its ability to help them.)

TummyTrials: Rigorous and low-burden testing of potential food triggers

Focus Area & Challenge
The specific patient-generated data challenge addressed

How can an app that guides low-burden testing of potential food triggers help patients conduct experiments on their diet to identify triggers related to unwanted symptoms?

Scope
The system within which the use case is taking place

- TummyTrials supports patients living with irritable bowel syndrome (IBS)—or who have similar symptoms without a diagnosed condition—as they test whether a particular food or nutrient triggers their symptoms. Patients can use TummyTrials on their own or work with a provider to plan the experiment, discuss results, and determine next steps.
- IBS is estimated to affect 10–20% of the US adult population; direct costs are estimated at $1.9 billion and indirect costs are estimated at $19.2 billion. [Source: *The burden of IBS: Looking at metrics*]
- While designed primarily for IBS, we envision TummyTrials as applying to a large range of food-triggered disorders and the general approach as applying to an even broader range of concerns.
- In the long term, we also envision aggregating data from many individual experiments to help new users determine which triggers they might wish to test first (e.g., the most common for people like them or the ones with the biggest effects on people like them).

Primary Actor

The person/people trying to achieve a successful outcome within this use case

Patient

- A person who suspects that foods/nutrients trigger or exacerbate their gastrointestinal symptoms.
- They want to experience reduced symptoms without over-constraining their diet (i.e., needlessly eliminating foods). They want to reduce their symptoms quickly, but they also want to get these answers with minimal disruption to their life.
- They are highly motivated because of the symptoms they regularly experience.
- Patients do not always trust the conclusions they draw, or the conclusions their providers draw, about whether a food or other activity (portion size, stress, physical activity) triggers their bowel symptoms. As a result, they may be reluctant to make behavior change decisions (e.g., avoiding or reducing consumption of a food) based on them.
- They would like to be empowered to make decisions about what to eat. To feel empowered, people need to have a good mental model of what happens to their symptoms if they eat a food, not that they have a blanket "okay" or "not okay" rule for each food.
- They would like to be confident that foods they are avoiding are worth avoiding, and that the ones they eat will not cause them unexpected distress.
- They would like to receive both emotional and instrumental support from their family and friends: They want friends to trust them when they say a food triggers their symptoms, and they want friends and family to be able to make informed choices about what to eat with them.

Stakeholders & Interests

The stakeholders and key interests that are impacted by this use case

Health providers (primary care physician, naturopath, or gastroenterologist)

- want to help the patient quickly and efficiently, bringing any medical/domain expertise to the problem
- want to make sure that providing care fits within their existing routines/workflows and billing structure

Family/friends

- want to help patient experience reduced symptoms but don't want to be unnecessarily inconvenienced in where or what they eat
- may be skeptical about whether patient's condition is real
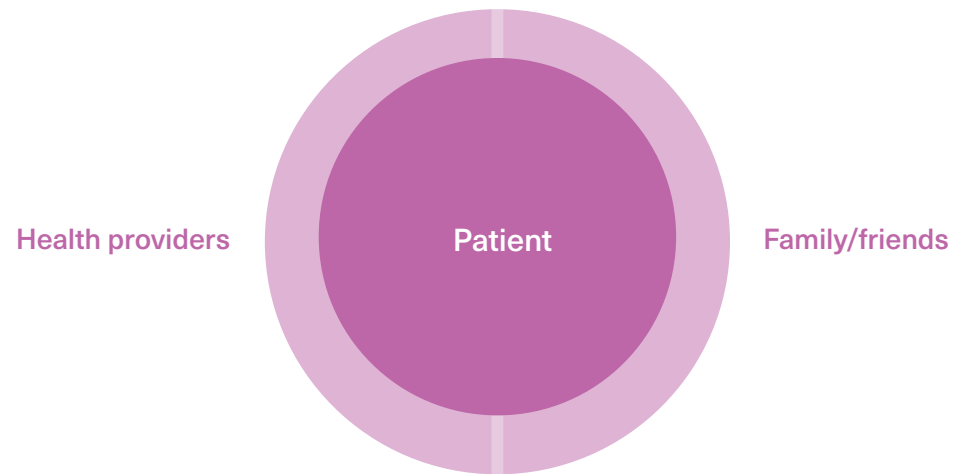
Health providers   Patient   Family/friends

Preconditions

The conditions that need to exist for this use case to be relevant or actionable

Patient

- Patient must have a hypothesis about a food-symptom relationship that can be tested (the framework could be expanded in the future—see the article "*A framework for self-experimentation in personalized health*" listed on page 27).
- Patient must believe that TummyTrials will help them to achieve their health goals without disproportional cost or effort (or at least less cost and effort, or a greater probability of success than other tools they have tried).
- Patient must be able to see the whole arc of how they might use Foodprint over the coming weeks or months.
- Patient must have smartphone compatible with TummyTrials mobile app.
- Patient must be comfortable having their data stored online.
- Patient must be able to engage in the experiment for 12 uninterrupted days.

Health provider

- Regulatory environment must not prevent patients from sharing data with their providers.
- Patient must have access to a health provider who is open to reviewing patient-generated data and engaging in collaborative review.

Triggers

The events or actions that start the use case

- Patient has (or thinks they could have) a hypothesis about the relationship between a food and one or more symptoms, and they know about the TummyTrials app from a peer recommendation or an internet search; or
- Healthcare provider recommends TummyTrials to patient to conduct an experiment, or healthcare provider may be involved in brainstorming which triggers to test first with the patient.

Minimum Guarantees

What will be achieved in the course of the use case, no matter what

- Patient learns more about the relationship between foods and their symptom(s), even if all that they learn is that the relationship is not strong or inconclusive.

Success Guarantees

The outcomes if the use case goal is successful

- Patient receives a result with a narrow enough credibility interval that they can confidently estimate the effect of eating a food on their symptom(s). That effect may be large or small.
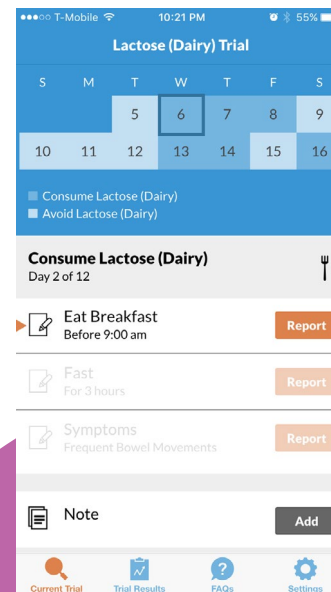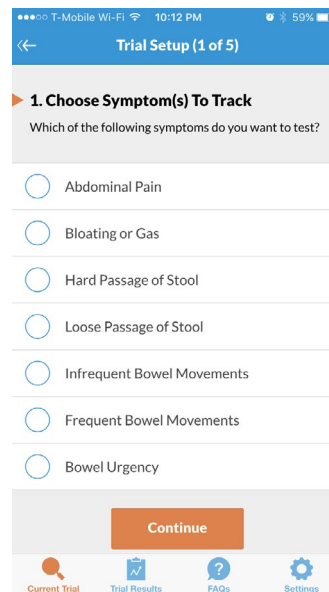
Success Scenario

The narrative sequence of events (steps) that lead from the preconditions and trigger to the completion of the goal by the primary actor

"If…then…"

Crucial breakdowns in the main Success Scenario steps, and the way in which the breakdown will be handled

1

Patient downloads TummyTrials application and registers an account.

If patients are not comfortable creating accounts and having their data stored online, **then** TummyTrials may consider an offline version or better educational materials about how information is stored.

2

Patient sets their hypothesis, default reminder times, and which symptoms they wish to track. (To identify one or more hypotheses to test, patient could receive help from a peer, a health provider, or the app).

If the app does not support the hypothesis that the patient wishes to test, **then** it will not work. **If** the app does not represent the symptoms that the patient wishes to track, **then** they can enter custom symptoms.

(It may also be possible to support custom trigger entry, but that requires the patient to have more domain knowledge about what is reasonable to test.)

3

Each day for 12 consecutive days, the patient consumes a meal according to instructions in the app and their experimental condition (for example, their base breakfast may be cereal, and on "on" days they use a lactose-based milk; on "off" days they use soy milk). Patient logs their compliance, fasts for three hours after eating, and then logs their symptoms. They can update this report until the end of the day. They can then eat what they want for the rest of the day.

If the patient misses a day or forgets to track, **then** the results become less valid and they must restart the experiment. (The patient must adhere to the experiment protocol for 12 consecutive days.)

If the food is not appropriate to test at breakfast (e.g., alcohol), **then** an alternative protocol is required for testing at meals.

4

After 12 days, the patient receives a report on the relationship between the food and the symptom.

5

Based on the results, the patient may:
- **a) develop a management plan (or work with their health provider to develop a management plan)**
- **b) conduct a second experiment with the same trigger, if the initial results are too inconclusive**
- **c) conduct another experiment with a new trigger, to test another hypothesis**

None of these steps need to be taken immediately.

Foodprint for Healthy Eating: Capturing and reviewing foods to identify opportunities for healthy eating

Focus Area & Challenge
The specific patient-generated data challenge addressed

How can a lightweight photo-based food diary mobile application empower patients to adopt healthy eating habits?

Scope
The system within which the use case is taking place

- Footprint Healthy Eating supports patients who want to make healthy changes in their eating habits, with a flexible system that patients can use on their own or in collaboration with a health provider.
- Obesity is a resource-intensive chronic illness affecting a large proportion of the US population and requiring lifelong monitoring and management. More than a third of the US adult population is obese, having a body mass index (BMI) of 30 or more [Source: *Prevalence of obesity and trends in the distribution of body mass index among US adults, 1999–2010*. JAMA; 307(5): 491-497]. Direct and indirect healthcare costs associated with obesity in the US were estimated at $75 billion in 2003 and projected to increase by $22 billion by 2020 and $66 billion by 2030 [Source: *Health and economic burden of the projected obesity trends in the USA and the UK*. The Lancet; 378(9793): 815-825].

Primary Actor

The person/people trying to achieve a
successful outcome within this use case

Patient

- A person who is interested in eating more healthily and improving their quality of life.
- They may or may not have identified specific healthy eating goals, for example, achieving weight loss or weight maintenance, having more energy at a particular time of day, eating less processed foods, or adopting a specific diet. (Foodprint is not designed for people who want to set and track goals with respect to a specific number of calories.)
- The patient wants to make changes (or determine that they don't need to make changes) with minimal effort and inconvenience. They don't want to give up too many things they enjoy, and they don't want their changes to get in the way of their other priorities in life.
- Motivation is a key challenge. Whereas Foodprint IBS users and TummyTrials users are highly motivated by their symptoms (see Use Cases 1 and 2), Foodprint Healthy Eating users may not have as much motivation to remain engaged.

Stakeholders & Interests

The stakeholders and key interests that are impacted
by this use case

Health providers (primary care physician, naturopath, or gastroenterologist)

- want to help the patient quickly and efficiently, bringing any medical/domain expertise to the problem
- want to make sure that providing care fits within their existing routines/workflows and billing structure
- may have concerns about whether they have sufficient expertise to advise on diet

Family/friends

- Eating behaviors are interconnected. Friends and families cook together and choose restaurants together. One or two family members may do the grocery shopping for a large family, influencing what they eat.
- These people may share healthy eating goals or they may have conflicting healthy eating goals. They also share other things that are important —cost, experience, and time together—and the Foodprint system and its recommendations should not get in the way of these.

Health providers   **Patient**   Family/friends
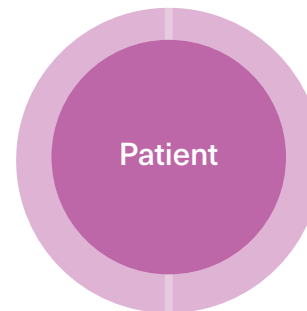
Preconditions

The conditions that need to exist for this use case to be relevant or actionable

Patient

- Patient must be interested in eating more healthily.
- Patient must be able to see the whole arc of how they might use Foodprint over the coming weeks or months.
- Patient must have a smartphone compatible with the Foodprint Healthy Eating mobile app.
- Patient must be comfortable having their data stored online.

Health provider

- Regulatory environment must not prevent patients from sharing data with their providers.
- Health provider must be open to reviewing patient-generated data and engaging in collaborative review, and feel that this work is valued by their organization or that it will save them time over alternatives.

Triggers

The events or actions that start the use case

- Patient who wants to engage in healthier eating finds out about the Foodprint Healthy Eating app from peers or an internet search;
- Health provider recommends tools (potentially Foodprint) to patient who asks about improving energy levels, mood, or weight loss, with the suggestion that the patient consider adjusting eating behaviors and that tracking could help; or
- Health provider recommends Foodprint to patient who expresses interest in healthy eating, with the suggestion that tracking could help the patient identify and monitor changes on their own, or could help facilitate a conversation at the next clinical visit.

Minimum Guarantees

What will be achieved in the course of the use case, no matter what

- Patient becomes more mindful of what they eat. If patient tracks variables in addition to food (for example, mood or energy), they should also learn more about the relationships between the foods they eat and how they feel.

Success Guarantees

The outcomes if the use case goal is successful

- Patient identifies aspects of their diet they wish to change and becomes more aware of the relationship between the foods they eat and their resulting mood or energy levels (if this interests them and they track mood/energy in addition to food). They may also determine they are already happy with their current eating behaviors.
- Patient feels more confident that they are eating in ways that support their overall goals while not feeling overly burdened or anxious about eating.
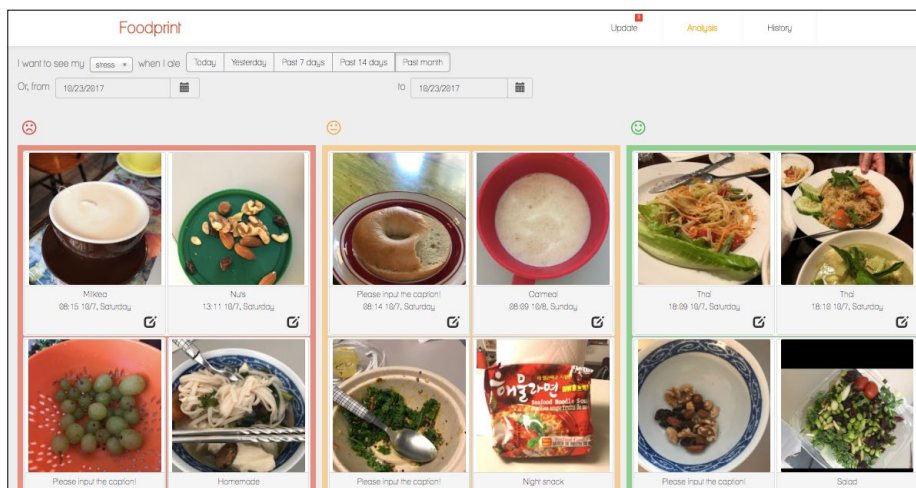
Success Scenario

The narrative sequence of events (steps) that lead from the preconditions and trigger to the completion of the goal by the primary actor

This suite of use cases includes three summary goals and no user goals. If further use cases were to be developed, then step 5 (Patient reviews the data) would be valuable to articulate in more detail as a user goal, as its success can have a cascading impact on the success of the subsequent steps.

"If…then…"

Crucial breakdowns in the main Success Scenario steps, and the way in which the breakdown will be handled

1

Patient downloads the Foodprint Healthy Eating application and registers an account.

If patients are not comfortable creating accounts and having their data stored online, **then** Foodprint may consider an offline version or better educational materials about how information is stored.

2

Patient configures their tracking, including selecting default reminder times and which data they wish to track.

If the app does not represent the data that the patient wishes to track, **then** they can enter custom data types.

3

Patient tracks what they eat and other data about their experiences for at least two weeks (though possibly not every day—they may follow a plan of three days on, three days off).

If patient forgets to track what they eat or other data of interest, **then** they can reconsider their strategies for remembering to track. For example, they might adjust their app notifications to make sure the timing of reminders suits their lifestyle, or they might ask friends/family or work colleagues to help them remember.

(**If** the patient fails to track the foods they eat or the symptoms they experience, **then** the system does not work effectively.)

4

[Optional* – Foodprint Healthy Eating does not currently support this step] A dietician (or, in the future, an automated system) codes the photos for constituent nutrients that are relevant to patient's goals, or, if the person has not a set a goal, according to some standardized recommendations.

If the patient has not recorded enough detail in their food entries, **then** it may be impossible to complete the photo coding.
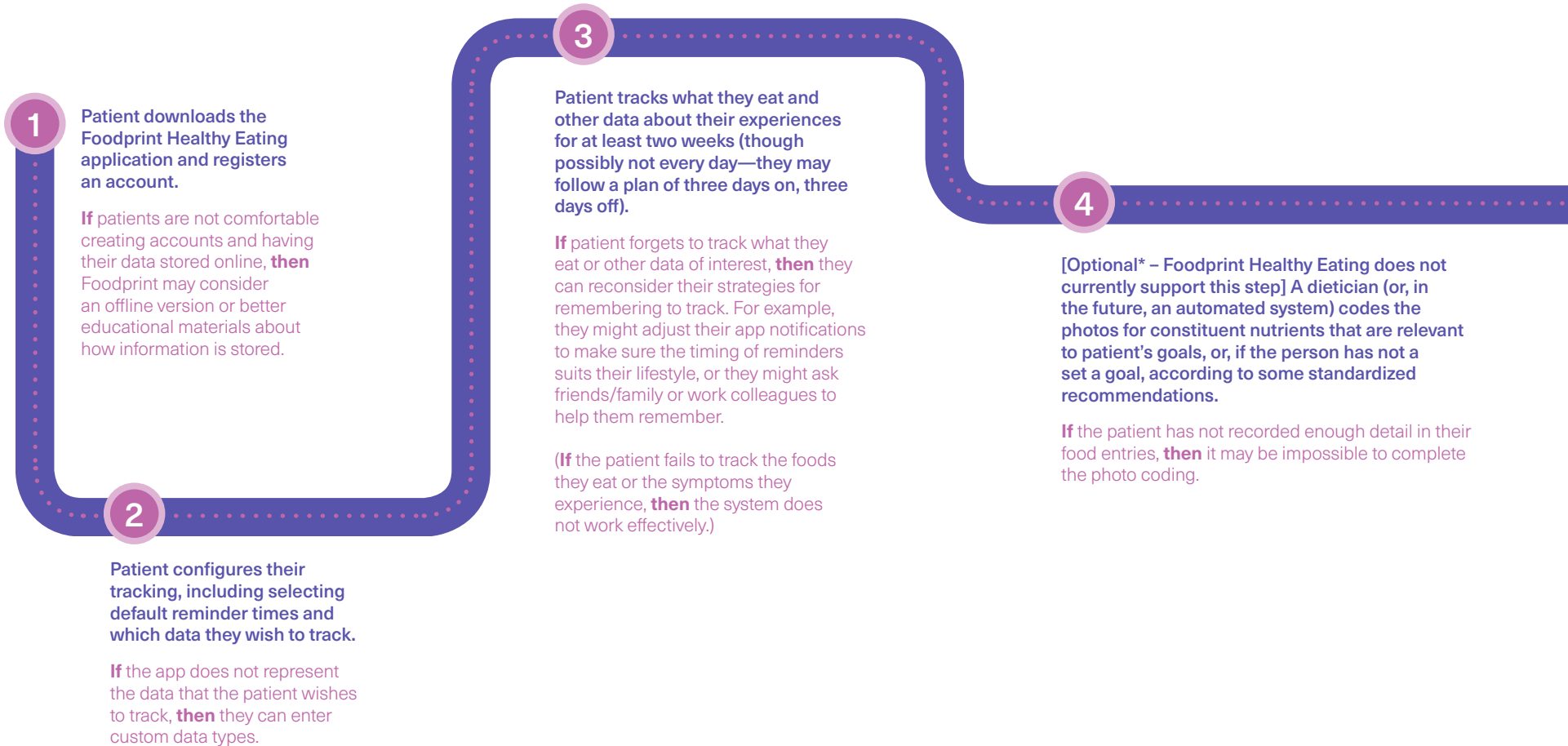
Success Scenario

The narrative sequence of events (steps) that lead from the preconditions and trigger to the completion of the goal by the primary actor

"If…then…"

Crucial breakdowns in the main Success Scenario steps, and the way in which the breakdown will be handled

5

Patient reviews the data. They may develop initial plans for change and/or things they wish to keep doing. They also may form questions that they wish to bring to their health provider, ask a peer, or conduct an internet search about (e.g., "I drink a lot of lattes. How healthy are they?") Based on the results, the patient may plan to adjust what they eat, how they prepare it, how often they eat it, or the portion sizes.

If the patient does not understand the grouping and visualization tools, **then** they can bring the data to their health provider or engage a friend/family member who understands the visualizations. They can also go back to step 4 if they skipped that optional step the first time and did not have their data coded by a dietician.

(Engaging these people requires that the patient have access to them. Future versions of the system could facilitate sharing the data on existing peer support forums or creating a peer community.)

6

[Optional*] Patient visits their health provider and they collaboratively review the data. The health provider offers additional perspectives. The web visualization facilitates this conversation, but it is patient-focused and patient-directed. They may plan to adjust what the patient eats, how they prepare it, or how they eat it. This could include foods they are happy to discover they can eat or foods they continue to wish to avoid.

If the health provider refuses to engage with the patient-generated data, **then** patient can connect with peers or seek a new provider who is trained in the Foodprint system and how to review its data.

*__Optional steps__ require additional human and financial resources, so a patient might choose to skip these steps if they believe they are unnecessary, especially because these steps are more costly (their insurance company might want the patient to skip these steps).

7

Based on the review (individual or collaborative), the patient enacts their plan for dietary or other changes. They may continue tracking while they do this, or they may choose to suspend tracking.

If the results are inconclusive or not actionable, **then** the patient can continue tracking to collect more data, depending on their goals. If the patient had wanted to check the overall health of their eating habits, they may be satisfied. **If** the patient had wanted to evaluate their diet to see if it might be causing or exacerbating other health concerns, **then** they may move on to evaluating other causes. They can also go back to step 4 if they skipped that optional step the first time and did not have their data coded by a dietician.

[As needed/desired] If the behavior changes do not result in desired/expected outcomes, then the patient can resume tracking. (In order to re-engage with the app, the patient must still have some confidence in its ability to help them.)

Related Information

Other information or details important to this suite of use cases

We have validated the Foodprint for Irritable Bowel Syndrome use case, including the supporting website and mobile app, with 16 patients and 8 providers. In fall 2017, we completed a pilot of the "Healthy Eating" version of Foodprint.

Emerging Questions

Further questions that surfaced from this work

> How much of the collection, analysis, and review of data can or should be automated? When and how should those processes be automated, and when is it important for patients and/or providers to be in the loop? How do we best match analyses to the types of questions people want to answer about their health? How can design help people understand the results of those analyses?

> What work is needed to include additional possible triggers (e.g., stress, physical activity, menstruation) in our tools for IBS management? How do we apply the process we have developed for IBS to health systems with more sporadic symptoms or where trigger-symptom relationships are cumulative and/or less immediate (e.g., migraine)?

> In the long term, who is the right health provider to review data collected by Foodprint? In our pilot studies, we have worked with gastroenterologists, primary care providers, and dieticians. For some questions, these may be the right people, but there may be roles for medical assistants and other—possibly new—professions in reviewing data as well.

> How can we help people move between different tools (e.g., from Foodprint IBS to Tummy Trials, or from Foodprint IBS to Foodprint Healthy Eating) as their goals change and their knowledge increases? For example, can someone who used Foodprint to manage their IBS symptoms re-use their data if they develop an interest in healthy eating?

Formative work

Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data. C Chung, K Dew, A Cole, J Zia, J Fogarty, JA Kientz, SA Munson. *CSCW* 2016. PDF | PubMed

More Than Telemonitoring: Health Provider Use and Nonuse of Life-Log Data in Irritable Bowel Syndrome and Weight Management. C Chung, J Cook, E Bales, J Zia, SA Munson. *JMIR.* Journal | PubMed

Download Alert: Understanding Gastroenterology Patients' Perspectives on Health-Related Smartphone Apps. JK Zia, T Le, SA Munson, MM Heitkemper, G Demiris*. Clinical and Translational Gastroenterology.* Publisher | PubMed

The feasibility, usability, and clinical utility of traditional paper food and symptom journals for patients with irritable bowel syndrome. JK Zia, C Chung, J Schroeder, SA Munson, JA Kientz, J Fogarty, E Bales, JM Schenk, MM Heitkemper. *Neurogastroenterology & Motility.* Publisher

Supporting Patient-Provider Collaboration to Identify Individual Triggers using Food and Symptom Journals. J Schroeder, J Hoffswell, C Chung, J Fogarty, SA Munson, J Zia. *CSCW* 2017. PDF | Publisher | PubMed

When Personal Tracking Becomes Social: Examining the Use of Instagram for Healthy Eating. C Chung, Elena Agapie, Jessica Schroeder, Sonali Mishra, James Fogarty, Sean Munson. *CHI* 2017. PDF

General views on self-experimentation

A framework for self-experimentation in personalized health. Karkar, R., Zia, J., Vilardaga, R., Mishra, S.R., Fogarty, J., Munson, S.A. and Kientz, J.A., 2015. *Journal of the American Medical Informatics Association, 23*(3), pp.440-448. Publisher

Feasibility and acceptability evaluation of the system

TummyTrials: A Feasibility Study of Using Self-Experimentation to Detect Individualized Food Triggers. Karkar, R., Schroeder, J., Epstein, D.A., Pina, L.R., Scofield, J., Fogarty, J., Kientz, J.A., Munson, S.A., Vilardaga, R. and Zia, J., 2017, May. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (pp. 6850-6863). ACM. Publisher

About Use Cases

Use cases—as a methodology—were designed to discover the "requirements" needed when designing computer software. These requirements are what the software system needs to be able to do for the "primary actor" who is seeking to achieve a goal. The requirements would tell the software designers what they need to build if the primary actor is to be successful in reaching their goal and alert them to the pitfalls that could be encountered along their journey. Important in this process is that "a use case only documents a process, it doesn't reengineer or redesign it." **Use cases are narratives that articulate the journey of someone (a "primary actor") as they interact with a system in order to achieve a goal.** An example would be someone logging into a website to find a specific piece of clothing, buy that piece of clothing, and have it shipped to their home.

For this initiative, we have taken the use case and adapted it to explore the question: "How might we enhance the collaborative use of patient-generated data among patients and providers to improve individual health outcomes?" While the use case methodology was originally designed to create solutions for mechanical systems, this adaptation offers a contextual shift in order to articulate solutions for a human social system. The work shared here is based on the work of Alistair Cockburn and his book *Writing Effective Use Cases*.

Articulating the Situation

The use case methodology is an effective way of articulating a current situation. When a group of people work together to identify key aspects of a situation, they create a shared understanding and build the design requirements: what must be considered as they develop a response to the current situation. The five areas a group needs to articulate to develop a use case are:

Scope
The scope identifies the boundaries of the current situation you are trying to address. There is no way to address the entirety of any situation, so we need to clearly delineate the area of focus for our work. This is also referred to as the **system under discussion (SuD)**.

Actors
This is the list of anyone or anything within your scope that has behavior. By "behavior," we mean anyone or anything that acts within the SuD. In this way, an actor can be a person, an organization, or a community.

Primary actor
The actor who initiates an interaction with the SuD to achieve a goal (and whose journey we follow through the use case).

Goal (and goal level)
This is naming what the primary actor is trying to achieve by interacting with the SuD. The two areas of focus with regard to the goal level are whether it is a **summary goal** (a goal whose achievement encompasses the entire SuD) or a **user goal** (a goal whose achievement completes a specific part of a summary goal within the SuD).

Stakeholder
Someone or something with a vested interest in either the primary actor or the system under discussion (SuD). A stakeholder is like an actor; the difference is that they may or may not behave within the SuD but are impacted or have interest in what occurs as a result of the behavior of the primary actor as they pursue their goal within the SuD. Communities are stakeholders when they are not acting within the SuD but rather have an interest or may be impacted by what happens as the primary actor seeks to achieve their goal.

Working Across a Continuum:
Creating greater levels of precision

There is no one way to apply the use case methodology in a healthcare setting. Rather, it is best to begin and then start iterating on what you create. Regardless of where you begin, there is real benefit in working on greater levels of precision on the use case as you move forward, both to frame your ongoing experiments and as a way of capturing the insights and options created by your work.

The first layer of precision is to articulate your best understanding of the five areas defined on the previous page. We are not trying to achieve a "right answer" with this work, but rather we are trying to articulate what we know now. Throughout the process, we can revise our previous work. With that in mind:

> What is the scope of your project?

> What are the boundaries of the situation you are looking to explore?

Now create a three-column list. In the first column, list all actors who have "behavior" within the scope identified. In the next column, name the goals that each of these actors have within the scope (what are they seeking to achieve?). In the last column, identify the goal level of these goals (is it a summary goal or a user goal?). Once you complete the list, circle the actors with summary goals. These are places to begin creating use cases.

Actor	Goal	Goal Level

There are three levels of detail you can work at while creating a use case: narrative use case, casual use case, and fully dressed use case. As a way of starting, we suggest you develop a narrative brief and then a casual use case for one of the primary actors. From that, you can begin to work and develop a fully dressed use case as you continue. At this point, these use cases end in success (and are therefore speculative). Later, when using them as a way for framing experiments, you will move the use case to being an outline of what needs to happen.

Narrative Use Case

This is a two- to six-sentence description of the actions of the primary actor as they pursue their goal within the SuD. The purpose is to get an understanding of the arc of the project and begin to get a sense of the complexity.

Casual Use Case

This builds on the narrative use case and begins to pull out detail in some areas. For this, you can use the following structure, filling in each area:

Use case name: usually the goal that is being pursued

Primary actor: identifying who they are or their role

Scope: brief outline of the situation and the boundary

Goal level: either summary goal or user goal

Main success scenario: the narrative of actions that the primary actor takes (and the reactions from the SuD) in achieving their goal

Fully Dressed Use Case

This is the most detailed version of the use case and is created in stages as you come to understand, through action, the nuances of the SuD. The structure for a fully dressed use case is:

Use case name: usually the goal that is being pursued

Context of use: a longer statement of the goal

Scope: outline of the situation and the boundary

Goal level: either summary goal or user goal

Primary actor: identifying who they are or their role

Stakeholders and interests: list of stakeholders and their key interests in the use case

Preconditions: what we expect is already the state of the world

Trigger: what starts the use case, which may be a time event

Minimum guarantees: what we can guarantee as outcomes, no matter what happens

Success guarantees: what happens if everything goes well

Main success scenario: the steps of the scenario, from trigger to the successful achievement of the goal by the primary actor (minimum of three steps, maximum of nine steps)

"If…, then…": the steps to take if there is a failure in one of the main success scenario steps

Related information: whatever additional information is important for your project

For an outline of the fully dressed use case, refer to the template (PDF) used by the research teams: **www.reospartners.com/pgd**

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