

Collaborative Healthcare Using Patient-Generated Data

# Using Patient-Generated Data Reports to Individualize Care for COPD

by Propeller Health

The background features a stylized illustration of two hands. On the left is a human hand in a light blue color, and on the right is a robotic hand in a darker blue color. The robotic hand is holding the human hand, symbolizing collaboration between human and machine. The background is a gradient of purple and blue.



Support for this initiative was provided by the Robert Wood Johnson Foundation. The views expressed here do not necessarily reflect the views of the Foundation.

Produced by Reos Partners  
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All the materials produced are available at the Reos Partners website:  
[www.reospartners.com/pgd](http://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* by Alistair Cockburn.

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# 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:

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## 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?

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## 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?

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## 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](http://www.reospartners.com/pgd)



### 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.

### 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.

### 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.

### 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
<b>Patient Generated Data Focus Area</b> <input type="checkbox"/> Shift Toward Trust <input type="checkbox"/> Mechanisms for Meaningful Collaboration Between Patient and Provider <input type="checkbox"/> Bring Patient Stories into the Clinical Encounter		<b>Patient Generated Data Challenge</b> Tell us about the specific challenge your team is trying to address within the focus area you have identified
<b>Use Case Name</b> The name should be the goal as a short action oriented statement		
<b>Design Scope</b> Describe the system within which the use case is taking place	<b>Goal Level</b> Is this a summary or a user-centered goal?	
<b>Primary Actor</b> Who is trying to achieve a successful outcome within this use case?	<b>Stakeholders &amp; Interests</b> List all stakeholders and key interests that are impacted by this use case	
<b>Preconditions</b> What conditions need to exist for this use case to be relevant or actionable?	<b>Triggers</b> What are the events or actions that start the use case?	
<b>Minimal Guarantees</b> What will be achieved in the course of the use case no matter what?	<b>Success Guarantees</b> What are the outcomes if the use case goal is successful?	



# Using Patient-Generated Data Reports to Individualize Care for COPD

by Propeller Health



## About This Use Case Suite

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**Chronic obstructive pulmonary disease (COPD)** is a chronic, progressive disease that can be challenging to treat. Patients living with COPD have lungs that are blocked or obstructed, making it hard for them to breathe. By adhering to prescribed medication, managing symptoms effectively, and avoiding exposure to irritants that cause further lung damage, a person with COPD may be able to improve their quality of life. However, there are challenges in creating individual and collaborative care plans. Patients struggle to objectively record and remember patterns in their medication use, while care providers can be skeptical of the reliability of what their patients report to them.

To address this challenge, Propeller Health created sensors that attach to COPD inhalers and passively record medication usage data, including time and location. Through Bluetooth technology, medication data is sent to the Propeller smartphone app, where robust analytics and machine learning build a personalized view of a patient's COPD. People with COPD can learn about their symptoms and triggers, receive medication reminders, and gain better understanding and insights about their COPD, among other benefits. Propeller can connect patients to their physicians and care teams through a Provider Portal and/or physician reports. The Propeller app, Provider Portal, and physician reports are objective, data-driven tools that display customized trends and insights in medication use. Use of the Propeller app or Provider Portal can accompany clinic visits and be powerful mechanisms in providing individualized care for COPD patients. This use case suite excludes the app and Provider Portal and only evaluates the physician report. This report is an objective, data-driven tool that can supplement patient reports of their symptoms and habits between clinical visits. It can be a powerful tool in providing individualized care for COPD patients.

For this intervention to be most effective, we considered adoption and use from the perspectives of both the patient and the provider. When centered around the physician, the priority of the use case is defining how this platform can be integrated as seamlessly as possible without requiring the physician and their clinical staff to alter their workflow. From the patient's perspective, our aim is to provide meaningful and interpretable information to promote self-management and help them receive the care they need.

This suite of use cases illuminates how Propeller can collect and report patient-generated data to empower patients and providers both inside and outside of the doctor's office.

### Research Team

#### Melissa Williams

CRT, AE-C, Director of Clinical Innovation, Propeller Health

#### Kelly Henderson

User Experience Research Lead, Propeller Health

#### Ki Han

Creative Director, Propeller Health

### Use Cases in this Suite

#### Summary

#### Use Cases **x2**

- 1 **Providers use patient-generated data reports for individualized COPD care**
- 2 **Patients use patient-generated data reports to advocate for individualized COPD care**

# Providers use patient-generated data reports for individualized COPD care



## Focus Area & Challenge

The specific patient-generated data challenge addressed

How can we use patient-generated data to address issues of limited objective data and a lack of trust between COPD patients and providers, to inspire a more collaborative care approach?

## Scope

The system within which the use case is taking place

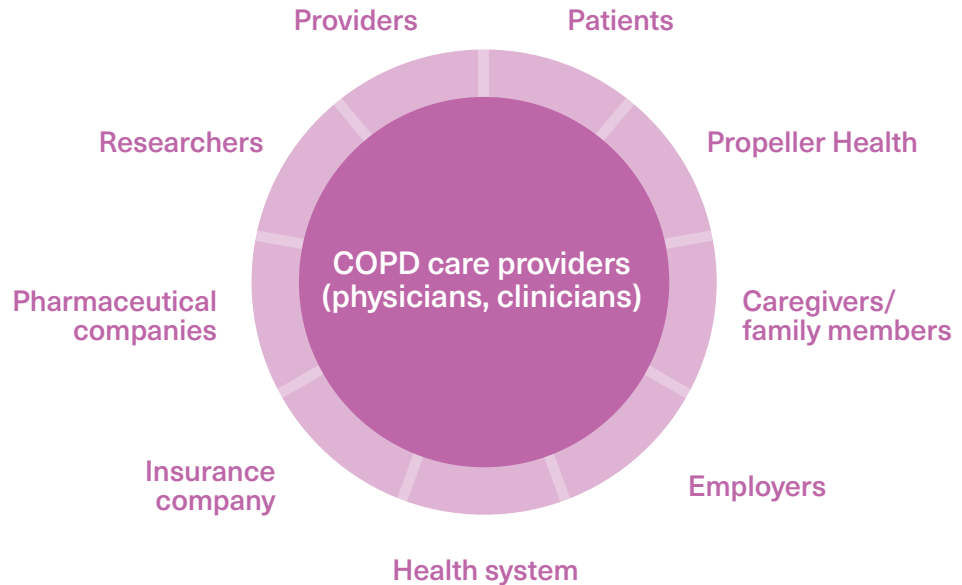
We are focused on the provider's ongoing monitoring and tracking of patients living with COPD.

**Primary Actor**

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

**COPD care providers**

- Physicians (i.e., pulmonologists, primary care)
- Clinicians (i.e., nurses, respiratory therapists, medical assistants, clinical administrative staff—patients typically spend more time with clinicians than with their physician)



**Stakeholders & Interests**

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

**Providers**

- quality of care
- ability to easily integrate patient-generated data into existing clinical workflow

**Patients**

- quality of life
- reducing symptoms and frequency of rescue inhaler use

**Propeller Health**

- providing products and a platform for managing respiratory health

**Caregivers/family members**

- ability to support the patient with COPD management at home
- ability to communicate with patient about their COPD and medication usage

**Employers**

- health of patient

**Health system**

- health of patients
- reducing frequency of hospital visits

**Insurance company**

- efficient and cost-effective care
- patient's use of medication

**Pharmaceutical companies**

- patient's adherence to correct use of medication

**Researchers**

- effect of different medications/usage on COPD

## Preconditions

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

### Patient

- Propeller must be able to integrate easily into patient's daily life.
- Patient must have inhaler(s) compatible with the Propeller sensors.
- Patient must be interested in managing their health and be committed and engaged as an active participant.
- Patient-generated data must be reliable in order for the patient to trust it.

### Providers

- Physician must be committed and engaged.
- Patient-generated data must be able to fit seamlessly into the existing clinical workflow without requiring more time or changes to routine.
- Patient-generated data must be reliable in order for the physician to trust it.

## Triggers

The events or actions that start the use case

- Provider recommends Propeller to patient during an appointment regarding their COPD;
- Patient is admitted to the hospital with uncontrolled COPD, and provider recommends Propeller program to help them understand and control their symptoms;
- Patient wants to learn more about their COPD, and they self-enroll directly with Propeller (some patients hear about Propeller through marketing campaigns or from their insurance company, and self-enroll on their own time online or by calling Propeller); or
- Caregiver enrolls patient to help support COPD management at home.

## Minimum Guarantees

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

- Patient-generated data is more objective for the provider's interpretation than self-reported data. There is no need to rely on the patient's self-reported data, which reduces the burden on the patient and may be considered less reliable than patient-generated data from the provider's perspective.
- Reports are received at key moments and regular intervals for interpretation by patient and provider.
- Data is digestible for both the patient and provider. The report is designed with a clear hierarchy of information, including a high-level snapshot and trends over time.

## Success Guarantees

The outcomes if the use case goal is successful

- Proactive care by the provider and early intervention for preventive care for the patient.
- Improved efficiency in appointments between patient and provider.
- Provider and patient can determine which medications work best for each patient.
- Informed touchpoints for patient and provider between appointments and hospital visits.
- Prevent patient visits to hospital/emergency room.
- Providers can identify trends in patient's adherence to prescribed daily medications.
- Improved efficiency of provider's follow-ups with patients (instead of calling a long list of patients who have recently visited the hospital with COPD concerns, the care team can know which patients require a follow-up call and focus on them).
- More specific and productive conversations between patient and other stakeholders, such as their family members, employer, and insurance provider.
- Patients are motivated and encouraged.
- Increased mutual trust between patient and provider.
- Improved standard of care by building trust and establishing more collaborative care between patient, provider, and other stakeholders.



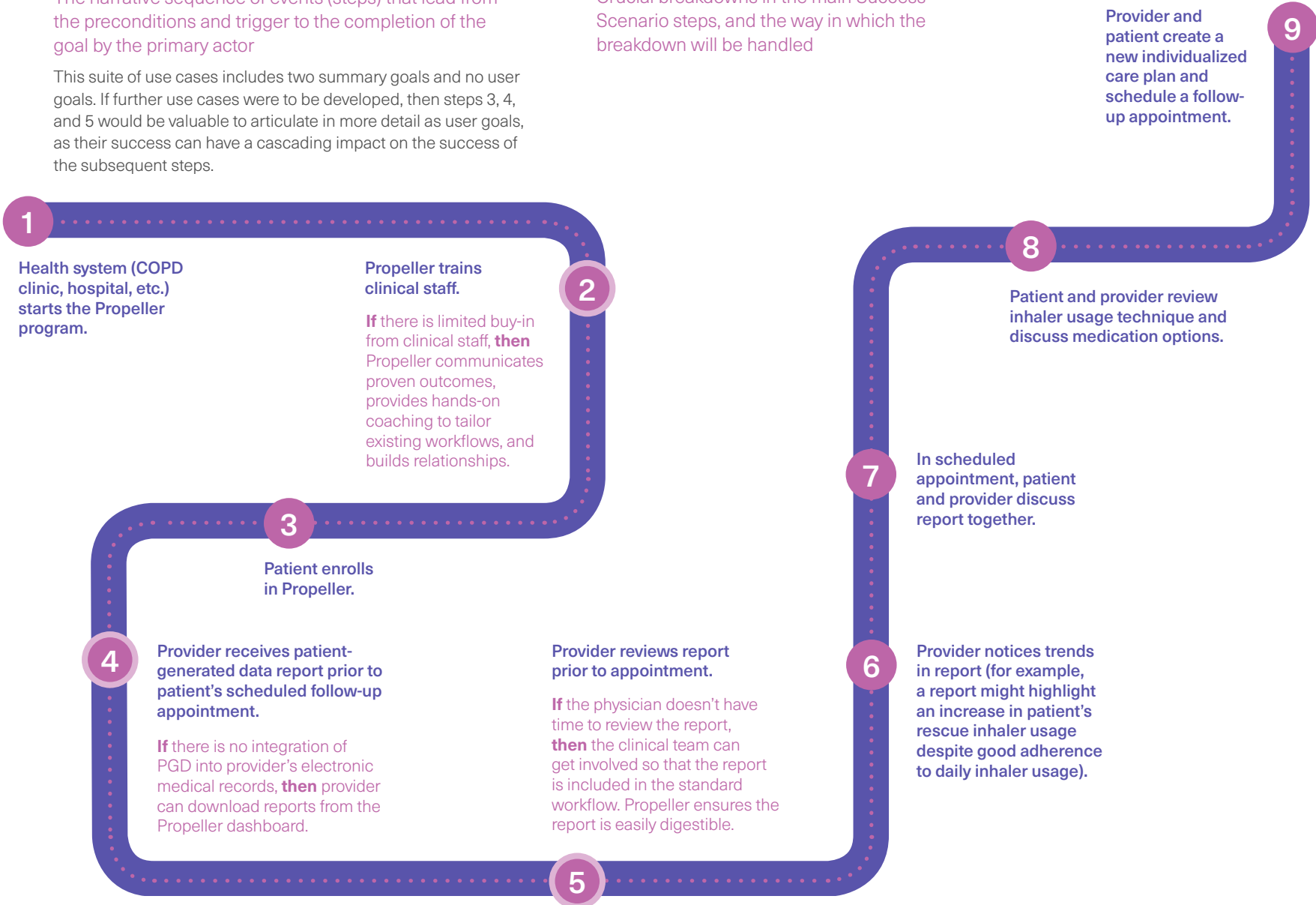
### Success Scenario

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 two summary goals and no user goals. If further use cases were to be developed, then steps 3, 4, and 5 would be valuable to articulate in more detail as user goals, as their 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



# Patients use patient-generated data reports to advocate for individualized COPD care



## Focus Area & Challenge

The specific patient-generated data challenge addressed

How can we use patient-generated data to address issues of limited objective data and a lack of trust between COPD patients and providers, to inspire a more collaborative care approach?

## Scope

The system within which the use case is taking place

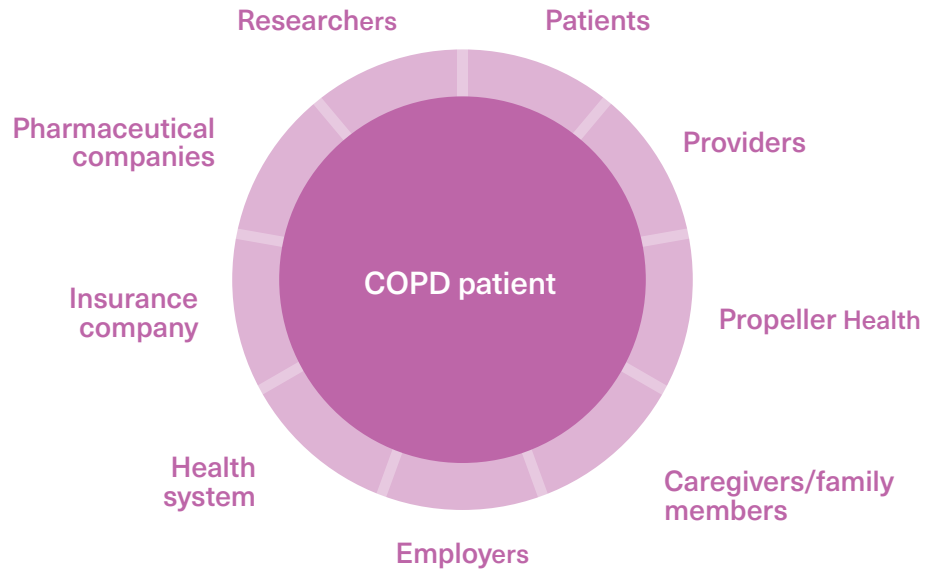
We are focused on the patient's ongoing tracking and monitoring of their COPD.

**Primary Actor**

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

**COPD patient**

- Person living with chronic obstructive pulmonary disease (COPD)



**Stakeholders & Interests**

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

**Patients**

- quality of life
- reducing symptoms and frequency of rescue inhaler use

**Providers**

- quality of care
- ability to easily integrate patient-generated data into the existing clinical workflow

**Propeller Health**

- providing products and a platform for managing respiratory health

**Caregivers/family members**

- ability to support the patient with COPD management at home
- ability to communicate with patient about their COPD and medication usage

**Employers**

- health of patient

**Health system**

- health of patients
- reducing frequency of hospital visits

**Insurance company**

- efficient care
- patient's use of medication

**Pharmaceutical companies**

- patient's adherence to correct use of medication

**Researchers**

- effect of different medications/usage on COPD



## Preconditions

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

### Patient

- Propeller must be able to integrate easily into patient's daily life.
- Patient must have inhaler(s) compatible with the Propellor sensors.
- Patient must be interested in managing their health and be committed and engaged as an active participant.
- Patient-generated data must be reliable in order for the patient to trust it.

### Providers

- Physician must be committed and engaged.
- Patient-generated data must be able to fit seamlessly into the existing clinical workflow without requiring more time or changes to routine.
- Patient-generated data must be reliable in order for the physician to trust it.

## Triggers

The events or actions that start the use case

- Provider recommends Propeller to patient during an appointment regarding their COPD;
- Patient is admitted to hospital with uncontrolled COPD, and provider recommends Propeller program to help them understand and control their symptoms;
- Patient wants to learn more about their COPD, and they self-enroll directly with Propeller (some patients hear about Propeller through marketing campaigns or from their insurance company, and self-enroll on their own time online or by calling Propeller); or
- Caregiver enrolls patient to help support management at home.

## Minimum Guarantees

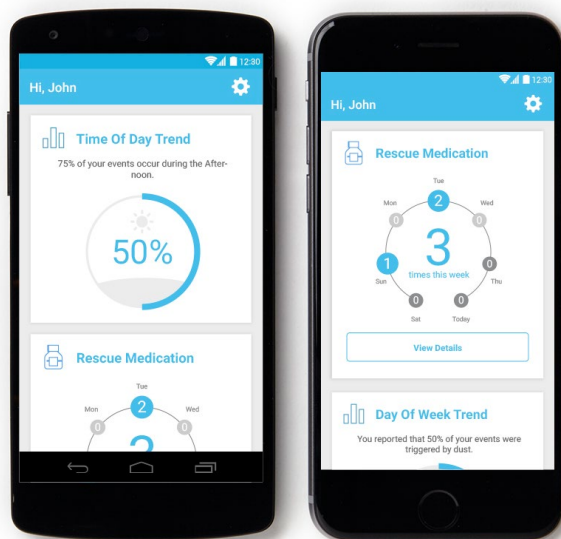
What will be achieved in the course of the use case, no matter what

- Patient receives reports detailing their medication use and trends. Patient is also able to see data in the Propeller smartphone app; however, this use case focuses on the reports.

## Success Guarantees

The outcomes if the use case goal is successful

- Patient gains new insights and becomes confident in their self-care.
- Patient gains confidence in speaking to their provider.
- Patient has more specific conversations with their provider about their experience between visits.
- Patient avoids visits to the hospital/emergency room.
- Patient feels heard and listened to by their provider.
- Trust is built among the patient, provider, and caregivers for more collaborative care.
- Patient has better adherence to daily medications.
- Patient can be treated proactively by provider; provider can reach out when needed between visits.



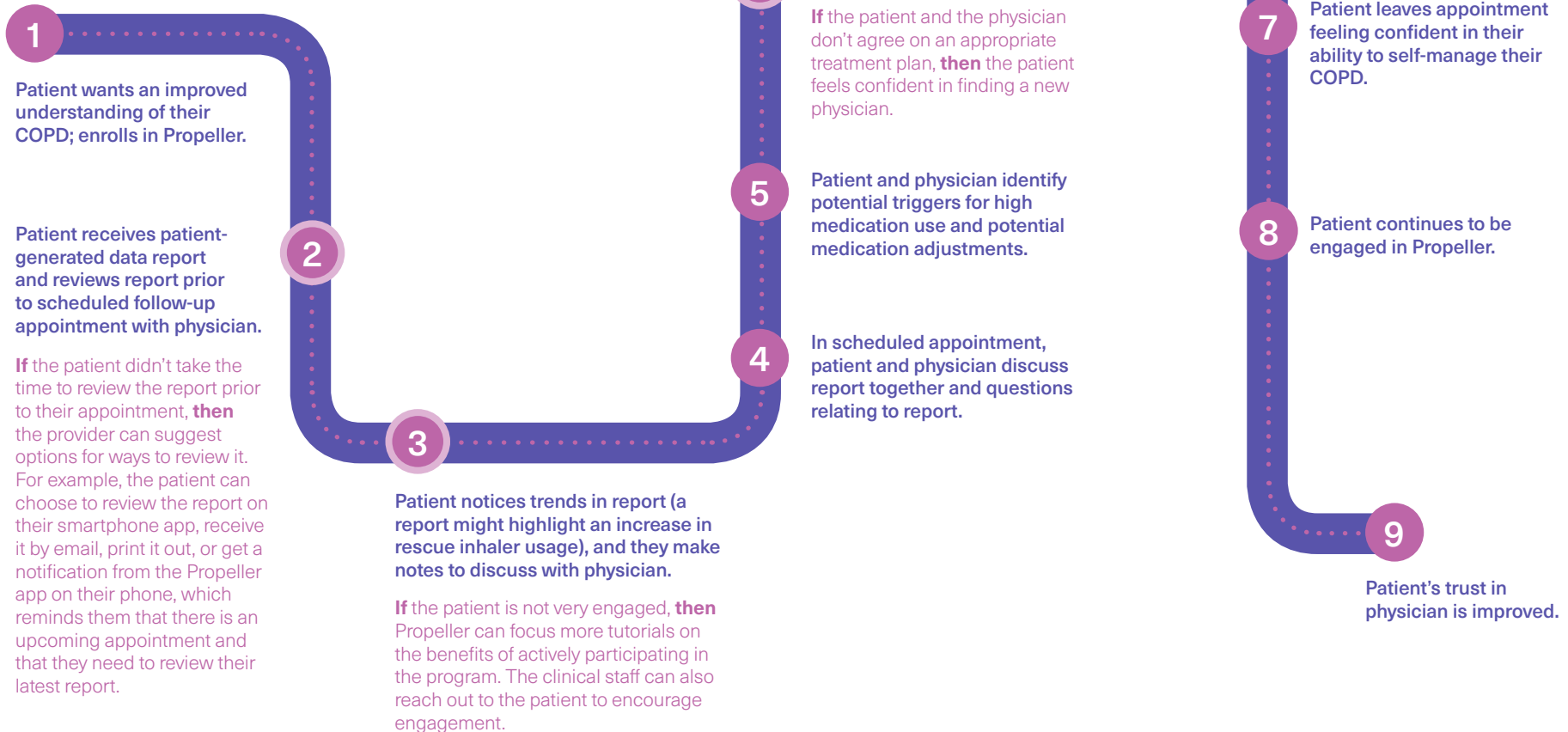
## Success Scenario

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 two summary goals and no user goals. If further use cases were to be developed, then steps 1, 2, and 8 would be valuable to articulate in more detail as user goals, as their 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



## Related Information

Other information or details important to this suite of use cases

More information about how the Propeller program works:

[www.propellerhealth.com/how-it-works/](http://www.propellerhealth.com/how-it-works/)

## Emerging Questions

Further questions that surfaced from this work

- > How can the reports best help build rapport between patients and physicians during and between appointments for diverse patient populations?
- > How can objective PGD and self-reported PGD be displayed in a complementary way within the reports to offer further insights for individualizing treatment plans?
- > What are the most effective ways to get reports into the hands of clinical teams to fit seamlessly into their existing workflows across various healthcare settings?

### 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](http://www.reospartners.com/pgd)



Reos Partners is an international social enterprise that helps people move forward together on their most important and intractable issues.

We design, facilitate, and guide processes that enable teams of stakeholders—even those who don't understand or agree with or trust one another—to make progress on their toughest challenges. Our approach is systemic, collaborative, and creative.

We partner with governments, corporations, and civil society organizations on challenges such as education, health, food, energy, environment, development, justice, security, and peace. Our work is pragmatic, professional, and tailored to the needs of the specific situation.

Our name comes from the Greek "rheos," which means "flow."

[www.reospartners.com](http://www.reospartners.com)



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