

# Making the Most of Patient Centricity

How to Be an Empowered, Engaged Patient



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As physicians, we are entrusted with a crucial duty, which is supporting the health of the patients we serve. We must listen actively to empower and provide patients with the necessary tools that would allow them to participate and be involved in their own healthcare decisions.

I believe patients teach us to be better physicians, as well as better scientists. We must put ourselves in their shoes to better understand their experiences. We know that we reach the best outcome for everyone when we

can treat patients holistically. Patients also lead us to ask the most relevant research questions to take to the bench, to really understand which part of our science can lead to a breakthrough and a solution for what they are going through.

As patients take an increasingly active role in managing their health, our goal is to help them make smart healthcare choices, improve their communication with doctors, and give them the information they need to advocate for themselves in a medical setting.

Patients are our North Star, and patient-centric initiatives are woven throughout our organization to ensure we're doing all we can to meet patients' needs. Each day we continue to build trusted, equitable and bidirectional relationships with patients and patient advocacy organizations to make sure patient voices are heard and amplified as we work to discover, develop and deliver breakthrough medicines and vaccines.

We hope the information in this book helps you and your loved ones learn more about your health and healthcare system, have informed conversations with your healthcare provider and make the best choices going forward.

Handwritten signature of Aida Habtezion in blue ink.

**Aida Habtezion, MD, MSc**

Chief Medical Officer & Head of Worldwide Medical & Safety  
Pfizer Inc.

Healthcare decision making should be a collaboration between patients and their providers.<sup>1</sup>

Think about the last time you were sick and you went to visit your doctor. Odds are, you were hopeful that the doctor had the correct medical knowledge to prescribe the right medications that could help you feel better. But unless you had the ability to accurately share how you were feeling, the doctor wouldn't have all the information necessary to offer you the best medical advice.<sup>2</sup>

In an ideal world, patients talk to their healthcare providers on a regular basis about what they're experiencing, what's important to them and what their concerns are.

In an ideal world, healthcare providers have built a trusting relationship with their patients, allowing them to work together to identify what's making a patient feel sick. They counsel the patient on what they can do to feel better, using language that is easy to understand and act on.

That ideal world has a name: "patient centric." In a patient-centric world, everything is done with the patient and for the patient.<sup>3</sup>

Pfizer's longstanding commitment is to place patients at the heart of the company's core principles.<sup>4</sup> "We're making breakthrough medicines and vaccines that change patients' lives," says Emma Andrews, Vice President for Patient Advocacy at Pfizer. "We cannot be successful unless we do that with patients."

This ebook is a part of Pfizer's mission to be patient centric. It's written for you—the patient, the caregiver, the member of a care team—to help empower you on your healthcare journey so you can be an engaged patient, one who understands the health information received in order to act upon it.



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My dream is for patients to be empowered, so when they're in front of their doctor they're able to have a conversation they can clearly understand.

— Emma Andrews

Throughout, we'll highlight resources that may be helpful as you navigate the complex world of health-care and provide you with questions to ask along the way. We hope it will provide a starting point for productive conversations with your healthcare provider and caregivers.

In the following pages, we will demonstrate the importance of participating in a health-literate society. We will offer insights about patient education programs, patient advocacy programs, and patient assistance programs that can inform, support and guide you through your health experience. We will describe the technology that's changing the future of healthcare, for the patient's convenience. And we'll show you how researchers are helping patients—and how patients are helping researchers—through clinical trials.

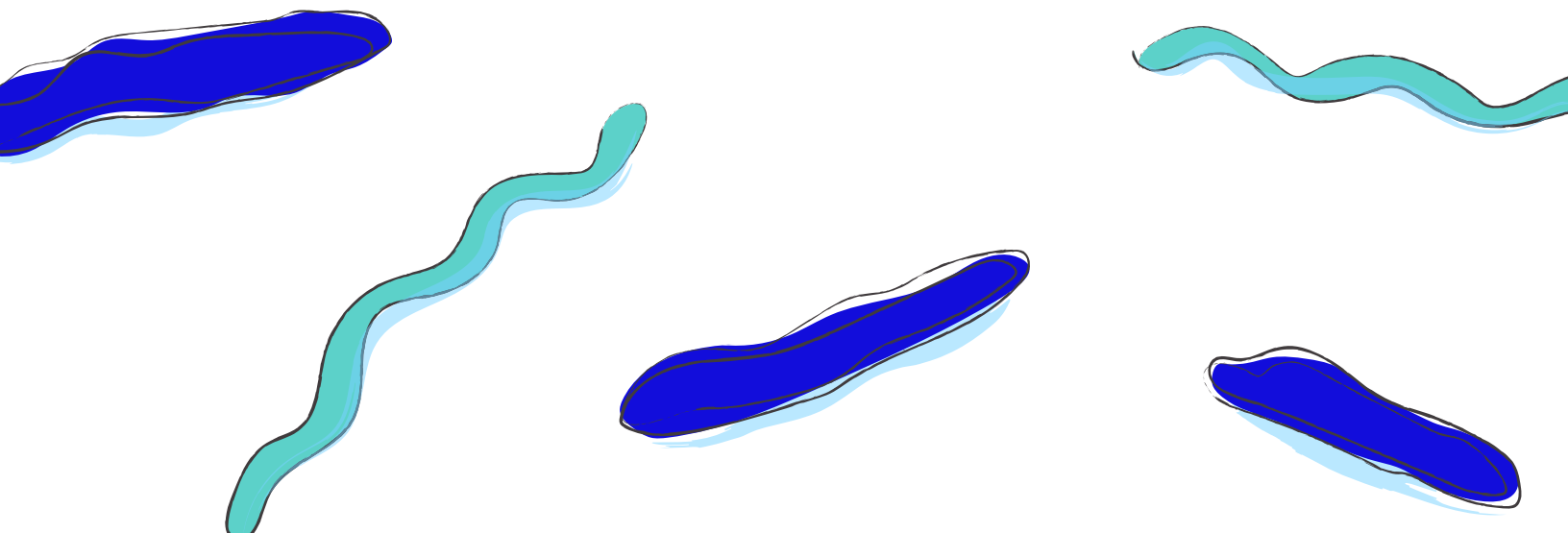
In each chapter, we've included suggestions for simple, direct questions you can ask medical professionals or helpful advice you can use. And in each section, we've included actionable tips. Together they may help you make decisions about your own care

and make the most of the patient-centric opportunities that are available to you.

Research shows that when a person understands their own health challenges and the treatments that are available to them, they're able to better assess the benefits and risks to make the decisions that are right for them in consultation with their healthcare provider.<sup>5</sup> Pfizer's purpose is the pursuit of breakthroughs that change patients' lives. To live up to that, it's important to provide easy-to-access information, written in plain language, so that you, as a patient, can make informed decisions<sup>6</sup> and be a true collaborator in your own healthcare.

"My dream is for patients to be empowered, so when they're in front of their doctor they're able to have a conversation they can clearly understand. They know exactly what the next steps are, and they act on that information," says Andrews.

We hope you can use this as a tool on your journey to becoming an empowered, activated patient!



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# Advancing Your Knowledge as a Patient

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Empowered patients are curious. They're driven to understand what others are saying, and to find resources that might help them address the challenges at hand. Empowered patients are willing and able to talk about their own personal priorities, in order to help others understand what they want and what they need.

In this section, you'll learn about what you can do to be an empowered and informed patient. That means taking advantage of health literacy opportunities and feeling encouraged to ask your healthcare team to communicate in a way that you can understand. It means being able to identify and access patient education programs that share reliable information about health conditions that matter to you and those you care about. It means speaking up about financial challenges and concerns and knowing how to find patient assistance programs that could help. And it means continuing to persevere, even when our complicated healthcare system presents challenges and obstacles.

Making the best possible choices for your own health starts with being armed with the right information to have a meaningful conversation with your medical provider. We hope you will find in these pages the information you need to start that conversation today.

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# In Plain Language

## How to Boost Your Health Literacy

If you've ever felt confused by health information, you're not alone. Nearly nine out of 10 adults in the United States struggle to understand and use health information when it's "unfamiliar, complex or jargon-filled," according to the Centers for Disease Control and Prevention (CDC).<sup>7</sup> When you consider some of the commonly used medical phrases—words such as comorbidity, idiopathic and subtherapeutic—it may sometimes feel like health-related vocabulary is meant to be unfamiliar, complex and jargon-filled.

"Personal health literacy" refers to the way someone finds, understands and acts on health information, while "organizational health literacy" refers to the way health-related information is made available

for a person to find, understand and act on.<sup>8</sup> Health literacy occurs when personal health literacy and organizational health literacy meet. In other words, it occurs when organizations share accessible, understandable information and patients find, understand and act upon it.<sup>9</sup>

A person who has good health literacy is empowered to communicate with their healthcare provider and make informed, shared decisions about their health and their treatments.<sup>10</sup> While health literacy is easy to confuse with general literacy, the concept goes far beyond one's ability to read; highly educated people may also find health literacy elusive.<sup>11</sup>



## How Pfizer is working to improve health literacy

Pfizer is committed to helping patients improve their health literacy by producing materials—including the results of clinical trials<sup>12</sup>—that are understandable, accessible and written in plain, consistent language.<sup>13</sup> Experts in health literacy at Northwestern University, in consultation with their patients, weigh in on whether the language Pfizer uses in its materials is understandable to all.<sup>14</sup> Knowledge is power—but first, the patient must be able to understand the language. Pfizer’s Plain Language Study Results Summaries (PLSRS) are helping to make it easier.

## Steps you can take to boost your health literacy

Health literacy is one crucial step toward addressing disparities in healthcare. In a world in which health equity and health literacy are successful, people would have equal access to high-quality, reputable information. That information would be written and shared in a manner that helps patients to truly understand it. As a result, patients would be empowered to use that information to make informed decisions about their care, use their medications safely and live healthier lives.<sup>15</sup>

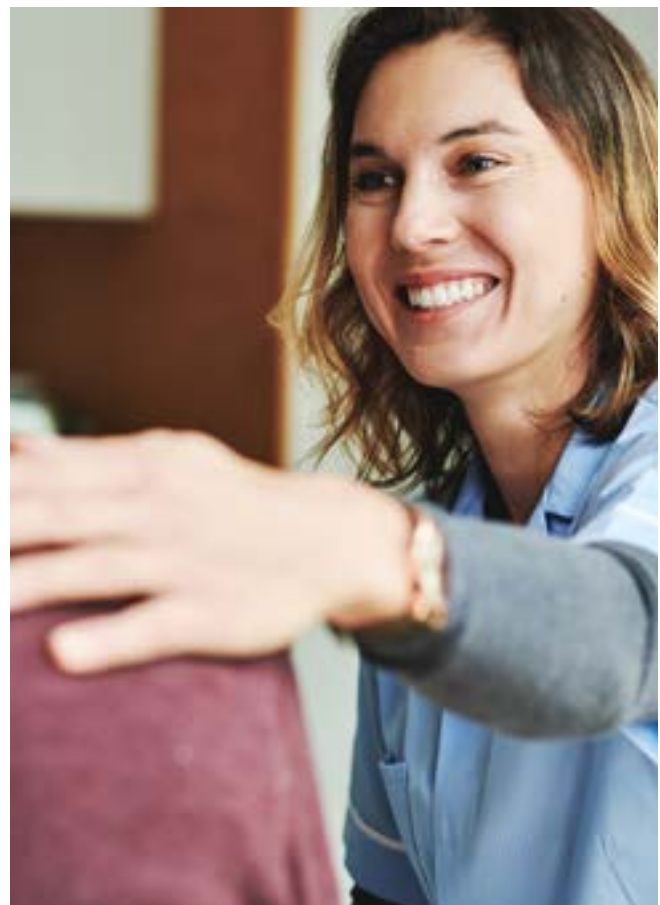
Those who don’t understand health information have been found to be more likely to suffer from chronic conditions, have trouble managing those conditions, avoid important medical tests and have higher rates of hospital and emergency room visits.<sup>16</sup>

You, as the patient, can play an active role in your healthcare management by taking advantage of health literacy opportunities. One good place to start is with Ask Me 3<sup>®17</sup>, a health literacy program geared toward helping patients take active roles in their healthcare.

**Ask your healthcare provider the following three questions during your next appointment:<sup>18</sup>**

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

If you don’t understand the answers, ask the healthcare professional to further explain it. Remember, this is your health and no question is off limits.<sup>19</sup> And if English isn’t your first language, ask, “Can I have a translator?” and request educational materials in your preferred language.<sup>20</sup>





# Patient Education Programs

## How to Find Credible Sources to Learn More About Your Health

Patient education programs can help patients make informed decisions about their care and treatment plans.<sup>21</sup> And while there's no shortage of information about health conditions, the key is knowing how to find information you can trust. Turning to "Dr. Google" can potentially lead you down a rabbit hole to information that could be incorrect, inapplicable or just plain frightening. That's why it's important to talk to your healthcare team and ask where you can find credible sources.<sup>22</sup>

### How Pfizer is involved with patient education programs

Pfizer colleagues are often experienced in specific diseases and medications.<sup>23</sup> To share that expertise, Pfizer often works independently and with other healthcare organizations to create, support and amplify educational materials and programs.<sup>24</sup> The goal is to provide reliable, factual information that patients may use to choose the right treatment in partnership with their healthcare provider.

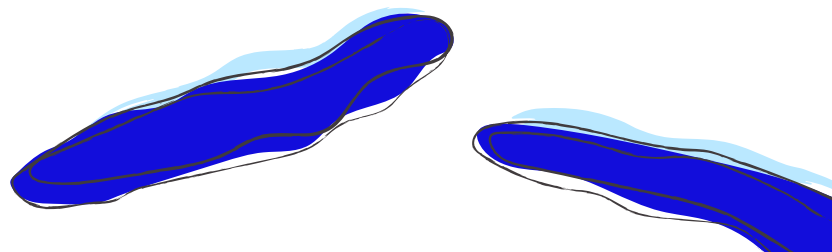
One example of a patient education program is Lung Cancer Profiles. [LungCancerProfiles.org](http://LungCancerProfiles.org) is a site full of resources and tips for biomarker testing and living with a non-small cell lung cancer diagnosis. Pfizer worked with a number of advocacy organizations to create this site, which aims to educate and raise awareness around a procedure called biomarker testing. Biomarker testing can assist a doctor and patient in choosing the appropriate treatment plan for their type of lung cancer.

### How to be an educated patient

Only you and your healthcare team and providers know your circumstances, including any other conditions you might have, values, and goals you hold, and personal or financial limitations you might be experiencing. They're the best resources to point you toward trustworthy materials.<sup>25</sup>

#### Here's how to make the most of those conversations<sup>26</sup>:

1. Be open with your healthcare team about your own values and goals. That way, they can work as your partner to help you find the right treatment at the right time.
2. Before acting on any information you find online or elsewhere, run it by your healthcare team. They know you and your circumstances best.
3. Ask your healthcare team about where you can find reliable information to learn more about your condition.



# Financial Assistance Programs

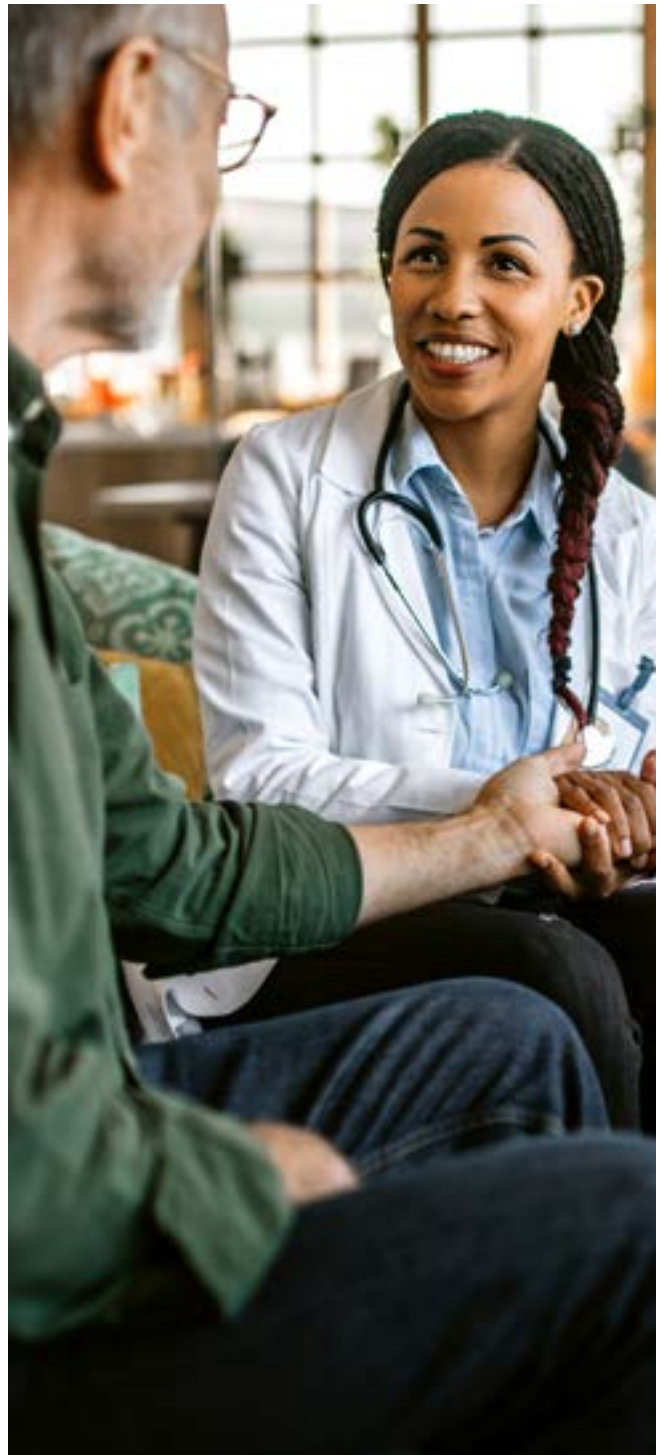
## How to Find Support to Pay for Your Medications

When a person can't afford their medications, they face some tough choices. According to a 2019 Gallup poll, 34 million people—or more than 13 percent of American adults—say they know of at least one friend or family member who died because they couldn't afford medical treatment.<sup>27</sup> In the same survey, 58 million adults reported they were unable to afford needed prescription medications in the last year.

Some people may not realize that help exists in the form of patient assistance programs, which can aid patients in accessing prescription drugs at little to no cost. Some of these programs may also help with other challenges a patient faces, such as offering transportation to and from appointments and connecting them with resources in their own communities.<sup>28</sup>

Charitable foundations and organizations may offer financial assistance to eligible under-insured patients.

Many pharmaceutical companies also have programs to help those who need financial assistance to afford their medicines, including, for example, [Merck Helps™](#), [Gilead Advancing Access® Program](#), [Lilly Cares® Foundation Patient Assistance](#), and [Pfizer RxPathways®](#). You may also find helpful information from organizations like [NeedyMeds.org](#), a non-profit organization that offers information about cost-saving opportunities for many medications.



## How Pfizer is involved with patient assistance programs

Pfizer believes that all patients deserve to live healthy lives.<sup>29</sup> Its patient assistance programs can help people access medicines that are safe, effective and affordable.<sup>30</sup>

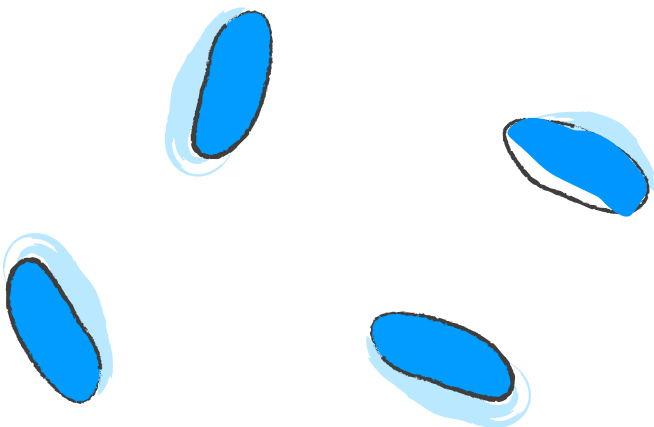
Pfizer RxPathways, for example, connects eligible patients to a range of programs that offer assistance in understanding insurance benefits and requirements, copay help and discounted or free prescription medicines. In 2020 alone, 136,000 patients received over 850,000 Pfizer prescriptions for free or at a savings.<sup>31</sup>

Another example is Pfizer Oncology Together, a free program for cancer patients who have been prescribed a Pfizer Oncology medicine. The program educates patients about financial assistance options, provides one-on-one support and guidance via a professional known as a Care Champion, and produces “The Skill Set” podcast, which shares real-world experience and advice for those living with cancer.

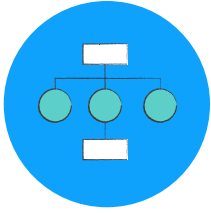
If you need help to afford your medications, it’s important that you are honest and open with your healthcare team by sharing that information.<sup>32</sup> It’s a sensitive subject, but they can’t begin to help you unless they know you need it.

### Questions to ask your health team about patient assistance programs:<sup>33</sup>

1. Do you know how much this medication will cost me?
2. Are there any programs available to assist with the out-of-pocket cost?
3. Who in this office will communicate with my insurance company to find out if the medication is covered?



## Advance Your Patient Knowledge & Empower Your Conversations



### Get organized

Start your own patient file—either paper or electronic—and fill it with the documentation you receive from healthcare providers, including lab results, notes, prescriptions and more. To help you keep track of conversations, make notes after each healthcare visit and add those to the file. Keep an ongoing, dated chart of your visits, their purposes and what the outcomes were.



### Write it down

Before you go to a doctor's appointment, write down any questions you have. That way, you won't forget to ask them, even if you get nervous or feel rushed. Keep an updated list of prescription and over-the-counter medications you take and the dosages. Whether you're visiting with a healthcare provider in person or virtually, having your medical history and data from all of your providers in one place can help you make the most of your time with your healthcare team.



### Find the right healthcare team for you

Seek healthcare providers who make you feel comfortable, respected and heard. Read reviews on reputable third-party sites, including your insurance provider's. Speak to patient advocates and current healthcare providers you trust for more recommendations. If you have a negative experience with a healthcare provider, or if you want a second opinion, meet with another provider. Repeat until you've found a good fit.



### Ask for help

It's common to need financial assistance to meet your healthcare needs. Many companies like Pfizer offer patient assistance programs to help patients with treatment affordability challenges. Some patient advocacy organizations also have support services that can help patients with healthcare cost and access issues as well. A number of organizations, like [NeedyMeds.org](https://www.NeedyMeds.org), provide information about savings on medications, including patient assistance programs and healthcare costs. Learn more about Pfizer's RxPathways patient assistance program by visiting the website or calling 1-844-989-PATH (7284).



### Ask questions (and then ask more questions)

If you don't completely understand something, ask your provider about it until it is explained to you in a way that you understand. If you are in a hospital setting, social workers and patient advocates may be available to help you navigate the system and gain more information.

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# Harnessing Patient-Centric Technology

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Technology is changing the relationship that patients have with their own health and the way they interact with their healthcare team.

Take wearables, for example. A device you wear on your wrist can track the beating of your heart, the distance you walk or the hours you sleep. That information could be transmitted to your healthcare provider to give them a fuller understanding of your health.

And then there's telehealth. Your phone and computer can serve as the gateway to a doctor's appointment, allowing you to forgo the commute and crowded waiting room, and instead connect with a healthcare provider from your own home or office.

In this section, you'll read about how technology is making the concept of patient centricity a reality every day, by allowing for convenient choices, centered around patient preferences.

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# Wearable Technology

## How to Use Connected Devices for Meeting Your Health Goals

Wearables like Fitbit® and Apple Watch®—devices that you attach to the body that contain sensors<sup>34</sup>—come in many forms: watches, rings, bands, glasses, phones, clothing, and the list goes on. Depending on the type of device, sensors might detect many kinds of things, such as changes in activity and heart rhythm. When the data is shared with healthcare professionals, including doctors and researchers, it can help them to better understand your health.<sup>35</sup> By collecting information at the convenience of the patient and allowing the patient to share data accurately and easily with healthcare providers, wearables truly epitomize patient centricity.

### How Pfizer is involved with wearable technology

Pfizer has started to use wearables in clinical trials to further understand study endpoints. One such study focuses on atopic dermatitis. This skin condition, which is the most common type of eczema, causes itching, rashes, and inflammation.<sup>36</sup> Wearables help the researchers understand when participants scratch and when they sleep, and the data may have the potential to support whether a study drug is potentially alleviating itching.<sup>37</sup>

For now, collecting and submitting data to regulatory agencies, like the U.S. Food and Drug Administration (FDA) and the European Medicines Agency, about the potential benefits of including wearables in trials has been the focus of Pfizer's efforts. So far, it has garnered positive early feedback. In the future, wearables could be used for increased communication





between patients and healthcare providers, and may even assist in managing complex diseases.<sup>38</sup> To better understand how wearables can be used in clinical trials, Pfizer has an entire lab dedicated to studying wearables and sensors, called the Pfizer Innovation Research Laboratory (PfIRe)<sup>39</sup>, in Cambridge, Mass.

## How you can make the most of wearable technology when it comes to your health

Activity trackers can help you monitor exercise and set goals reminding you to increase your movement.<sup>40</sup> Some healthcare providers might find the data you collect useful as you work together to address your healthcare needs. And, if you're a study participant in a clinical trial, wearables could even be a convenient way to communicate your data to the study doctor.

### To bring wearables into your own routine, ask your healthcare provider these questions:

1. Are there activity trackers/wearables you would recommend?
2. What kinds of activity should I track?
3. Are there particular activity goals I should set?
4. Is there any data I could collect that your medical practice is interested in tracking, in order to better understand my health?



# Plug into Telemedicine

## Use Technology to Bring Healthcare into Your Home

Today, healthcare doesn't necessarily require an in-person visit. Telemedicine allows patients to use their computer or smart phone to meet with healthcare providers at their own convenience via video or voice call.<sup>41</sup> Patients can talk with mental health professionals, out-of-town specialists, and even participate in virtual clinical trials—which Pfizer was conducting as far back as 2011<sup>42</sup>—all from the comfort of their own couch.

### Should you consider telemedicine?

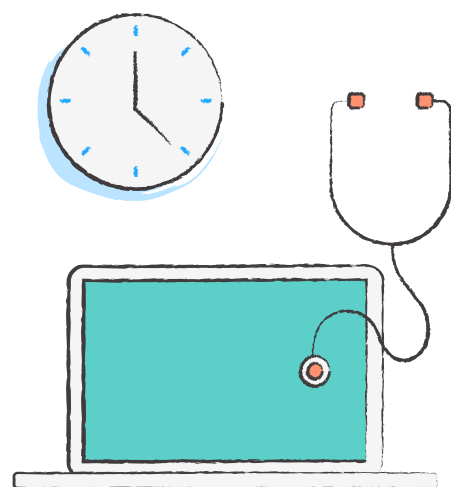
Telemedicine makes it easier than ever to receive medical care. All you need is a connected device and an appointment and, voila! The doctor will see you now. Telehealth goes hand in hand with patient centricity because of how easily it can fit into your routine.

Telehealth is helpful for an array of health services. A few examples include COVID-19 screening, access to primary care providers and specialists, coaching for chronic health conditions, follow-up after hospitalization, nutritional counseling, medication management, physical therapy, occupational therapy, mental and behavioral health counseling.<sup>43</sup> It can also be useful for patients such as rural residents, older adults, or people with mobility issues who may face challenges in getting to an in-person appointment.<sup>44</sup>

### Some of the benefits of telemedicine include:<sup>45</sup>

- No time spent getting to and from appointments
- Saved costs on transportation and childcare
- Reduced wait times
- Access to specialists who are far away
- Reduced risk of being exposed to germs

For those who are shy or introverted and those who feel embarrassed talking about sensitive health topics, virtual visits can also provide a greater level of personal comfort.

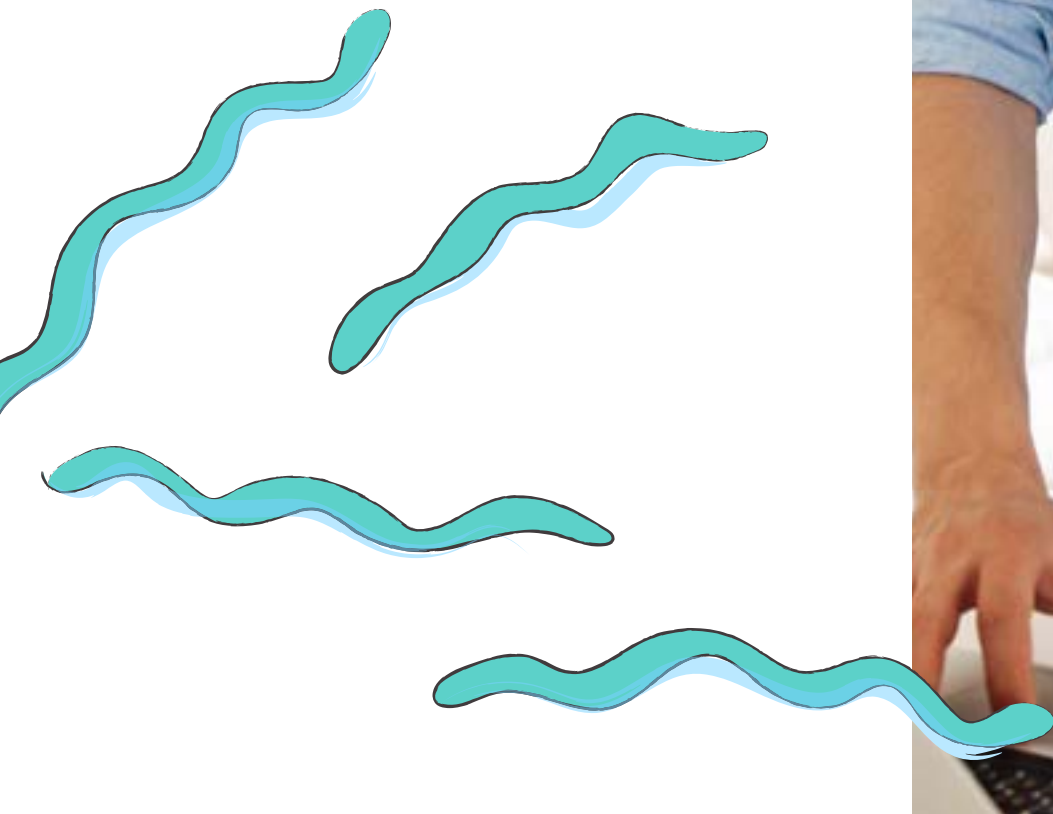


## How to prepare for a telehealth visit

If you're ready to try telehealth, being prepared for your virtual visit can have a positive impact on how beneficial the meeting can be.

### Here are a few ways you can get ready for your appointment:<sup>46</sup>

1. If you need an interpreter, let the healthcare team know in advance of the appointment.
2. Make sure your internet connection is working.
3. Check your email for instructions about how to use the technology for an appointment.
4. Write down information such as medications you're taking, symptoms you're experiencing and concerns you wish to share, and keep the information close by.
5. Find a quiet room, if possible, so you can hear the healthcare provider and they can hear you.

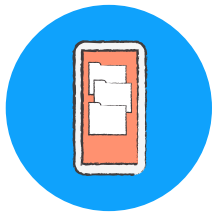


## Harness User-Friendly Technology



### Take advantage of telemedicine

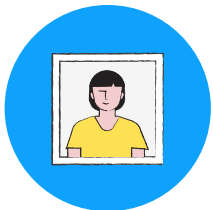
Find out what video conferencing platform your healthcare provider uses when you make the appointment. If the platform is new to you, set up your account in advance. Even if you've used it before, schedule a test call with a friend or family member to make sure your audio and video are working the way they should, to avoid the need to troubleshoot during your appointment and disrupting the call with your healthcare provider.



### Create your own online database

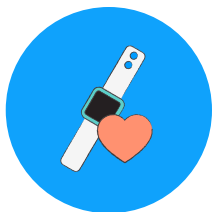
Using a browser on your computer or mobile phone, create a bookmark folder where you can save your healthcare-related website pages in one place. Here are some examples of web pages that are worth bookmarking:

- Information and contact pages for each of your healthcare providers
- Trusted information pages about your condition or disease
- Contact information pages for your insurance providers
- Trusted pages with descriptions of each medication you're prescribed and any over-the-counter medications you take regularly



### Access patient portals

A patient portal is a secure website that often offers access to notes about your visits, lists the medications you've been prescribed, archives your lab results, allows you to communicate with your healthcare provider and provides the ability to pay your bills online. Ask your healthcare provider if they offer patient portals and how you can sign up.



### Connect with wearables

Invest in a wearable device and connect it to an app on your computer or mobile device to track and review your own statistics. If the cost of the wearable is prohibitive, check with your health insurance providers, as some may cover or offer special rates for certain devices. While some wearable devices are still labeled for general health, and are therefore not automatically eligible, if you are able to get a letter of medical necessity (LMN) from your healthcare provider, you may be able to use a flexible spending account (FSA) or health savings account (HSA) to purchase a device with pretax money.

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# Cultivating Collaboration & Participation for Better Healthcare

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Just as patients learn from healthcare providers and researchers, healthcare providers and researchers learn from patients.

In this section, you'll read about how collaboration and participation of people like you are key to making the healthcare system more patient centric. Through patient advocacy groups, patients can receive support and connect with others like them. They can also share their own experiences to help healthcare professionals—including researchers at Pfizer and other pharmaceutical companies—understand what they're going through and what they might need. And by participating in clinical trials, patients can help advance science by helping researchers learn about whether potential treatments are safe and effective.

By elevating their voices and sharing their experiences, patients are helping to shape the future of medicine, making it more patient-centric along the way.

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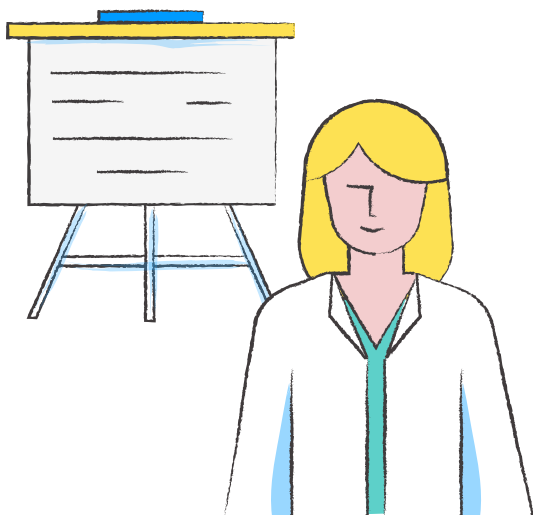


# Patient Advocacy Groups

## How to Find Non-Profit Organizations That Can Help You Better Understand Your Health

When you're first diagnosed with a health condition, you may feel as though you have more questions than answers. Patient organizations or patient advocacy groups may be able to help answer those questions.

A patient advocacy group is generally a non-profit organization that focuses on a particular condition and helps people with that condition.<sup>47</sup> The group may offer education, psychosocial support and financial assistance. It may also share information about treatment options, offer funding for research and advocate for policy change.<sup>48</sup> Some examples of advocacy groups include American Cancer Society, American Heart Association, American Lung Association, Arthritis Foundation, National Organization for Rare Disorders (NORD) and National Hemophilia Foundation.



### How Pfizer is involved with patient advocacy groups

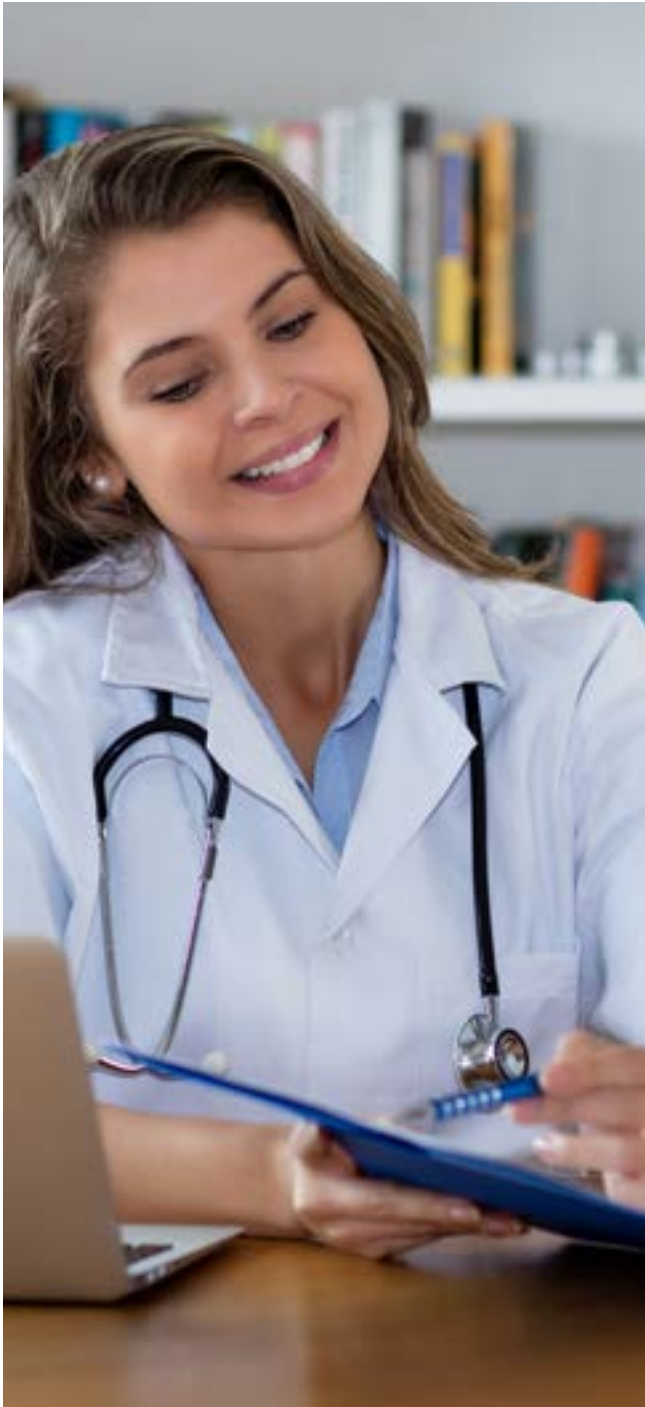
Pfizer works with hundreds of advocacy organizations in a variety of ways:<sup>49</sup> to learn from patients' experiences with a condition or treatment, to inform patients about clinical trials, to discuss side effects or side effect management, to educate the health-care community about tools that might be helpful to patients, to amplify messages from those organizations and to host or co-host informative webinars.<sup>50</sup> By working with patient advocacy groups, Pfizer is able to connect with patients and get their direct feedback. Those patient voices may help to shape future research and development, manufacturing decisions, clinical trial design, and access to medicine and information.<sup>51</sup>

For example, Pfizer created the Pfizer Oncology Patient Centric Ecosystem (POPCE) in 2019 in an effort to further embed patient insights and experiences into its work to support people affected by cancer. POPCE brings Pfizer leaders together with more than 45 advocacy organizations and professional societies to meet regularly and discuss ways to better understand patient needs and build programs for patients.<sup>52</sup> The group focuses on topics such as health literacy, engaging patients in clinical research, and reducing health disparities.<sup>53,54</sup>



## How patients can learn more about patient advocacy groups

To find out if there's a patient advocacy group that may be helpful to you, do a bit of research and vet your findings with your HCP team.



### Here are a few things to bear in mind as you evaluate whether an organization is a good fit for you:

1. Is the organization a registered non-profit, 501(c)3 with a board of directors? (This information is usually found in the "About Us" section of the website.)
2. Does the organization provide information on the disease that is referenced from peer-reviewed, published materials?
3. Does the organization provide information and services that are of interest to you?

### You can also ask your healthcare team these questions:

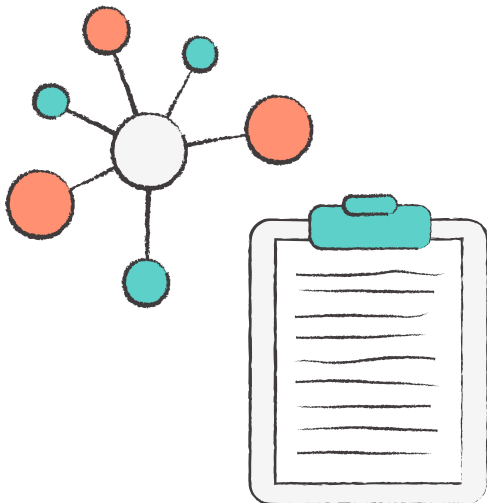
1. Is there a patient advocacy group that could help me learn more about my condition?<sup>55</sup>
2. What are the services that group offers?<sup>56</sup>
3. Is there a forum you can recommend where I can connect with other patients who may be going through experiences similar to my own?<sup>57</sup>

# About Clinical Trials

## How to Receive Care and Help Advance Science and Medicine by Participating in Research Studies

Clinical trials study whether potential treatments are safe for humans, and if they work as intended in treating or preventing disease.<sup>58</sup> Researchers seek to include people of diverse backgrounds, including socio-economic status, ethnicity, race, gender, age and other characteristics;<sup>59</sup> to learn about how a potential vaccine or medicine works within those groups;<sup>60</sup> to reduce health disparities; and to improve the development of health products for all.<sup>61</sup>

The Center for Information and Study on Clinical Research Participation (CISCRP) is a non-profit organization that is dedicated to educating people about clinical research. According to CISCRP, some of the potential benefits of being a study participant include playing an active role in your own health experience and helping to further scientific research.<sup>62</sup>



### How Pfizer prioritizes study participants in clinical trials

Pfizer listens to patients and advocacy groups, and their voices help to shape the designs of clinical trials, making them more patient-friendly.<sup>63</sup> That begins with outreach, which aims to help the clinical trial seeker answer questions and access information in a language that is easy to understand.<sup>64</sup> Many clinical trials also have a pre-screener to help patients determine if they're eligible to participate.<sup>65</sup> If a patient is accepted into a clinical trial, Pfizer works to make it convenient, which in some cases can mean eliminating office visits, conducting blood draws at home, and delivering potential treatments to the patient.<sup>66</sup> So that participants can learn more about the trial and their role in it, Pfizer publishes results of studies in plain language that adults of all education levels can understand.<sup>67</sup>

People participate in clinical trials for different reasons. Some may be healthy volunteers who are looking to make an impact; others may have a disease and are interested in receiving a potential new treatment.<sup>68</sup> Patient participation is critical to successful clinical trials, and Pfizer has its own gratitude program to show its thanks to participants.<sup>69</sup> Whatever the reason, by joining a clinical trial, participants are helping to advance science and medicine.<sup>70</sup>

**Want to help advance science by participating in a clinical trial? You can get started by talking to your healthcare provider and asking these questions:<sup>71</sup>**

1. Have you heard of any clinical trials I could join that address my disease?
2. What kinds of tests and treatments are involved?
3. With whom can I speak about questions and concerns?

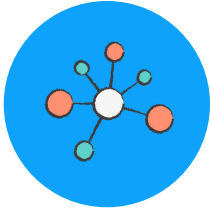
If you decide to participate in a clinical trial, be sure to ask where you can learn about patients' rights for clinical trial participants, and get up to speed on issues such as your safety and your privacy.<sup>72</sup>

To learn about clinical trials that might be a fit for you, visit CISCRP's search site via [CISCRP.org](https://www.ciscrp.org) or visit the U.S. National Library of Medicine's clinical trial finder at [ClinicalTrials.gov](https://clinicaltrials.gov).

If a clinical trial isn't an option, and you've exhausted all treatments, health authorities may grant permission to a company like Pfizer to provide a drug that hasn't yet been approved to a treating physician. that hasn't yet been approved. This is called "compassionate use" or "expanded access."<sup>73</sup> To learn more, visit [PfizerCares.com](https://www.pfizer.com/clinical-trials).



## Cultivate Collaboration & Partnership for Better Healthcare



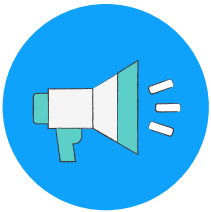
### Create a personal healthcare network

Make sure you share the same information with all of your healthcare providers, such as the names and contact information for all of your other providers, the advice you've received, the medications you've been prescribed and the results of lab tests. Ask your primary care physician to serve as a central contact for your whole healthcare network to coordinate your care and avoid contradictory advice.



### Participate in online patient communities

Finding and speaking with people around the world who share your experiences with a condition or disease can offer emotional support and positive encouragement. Do your research before joining a group so you understand the measures being taken to protect your privacy as a patient before you share any information about yourself. A great place to start is by contacting a relevant patient advocacy group to ask for recommendations or checking with your healthcare provider.



### Raise your voice

A patient-centric world depends on you—the patient—to share your experiences. Find ways to raise your voice and offer a deeper understanding of the patient experience. Ways to do this include participation in patient forums, patient advocacy groups and clinical trials. Share what matters to you with your healthcare team and healthcare administrators. If you're interested in sharing your story with others, indicate that to patient advocacy groups and healthcare providers, in case an opportunity arises to talk to media or give testimony before government officials.



### Consider participating in a clinical trial

Clinical trials help advance science and medicine and rely on willing participants. Some people enroll in clinical trials to receive a potential new treatment and additional care; others are interested in making an impact. If you're interested in participating in a clinical trial, ask your healthcare provider or visit [ClinicalTrials.gov](https://ClinicalTrials.gov) or [PfizerClinicalTrials.com](https://PfizerClinicalTrials.com).

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# Your Responsibility as an Empowered, Engaged Patient

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Now that you've learned about some of the efforts that organizations such as Pfizer are making to be patient-centric, and you've read about resources available to help you in your health experience, it's time to think about your role as an empowered patient.

"The onus is on us to do what we can to be patient-centric, but that doesn't mean the responsibility is taken away from the patient," says Emma Andrews, Vice President, Patient Advocacy Lead with Pfizer. "The patients, at the end of the day, are responsible for their own health and owning their health."

Empowered patients ask questions, request clarity until they understand the answer and act on the information. Empowered patients open up and share personal information with their healthcare provider. Empowered patients enter into every healthcare encounter understanding it's a collaboration and a responsibility, and they rise to the occasion to play an active role in their health plan.

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1. Andrews, Emma. Interview by Kate Silver. 10/19/21.
2. Andrews, Emma. Interview by Kate Silver. 10/19/21.
3. Andrews, Emma. Interview by Kate Silver. 10/19/21.
4. Andrews, Emma. Interview by Kate Silver. 10/19/21.
5. Via transcript of interview with Annlouise Assaf. [Empowering Patients by Closing the Health Literacy Gap](#). Accessed 10/7/21.
6. Pfizer Health Literacy Position Statement. Available at [https://cdn.pfizer.com/pfizer.com/Pfizer\\_Health\\_Literacy\\_Position\\_Paper.pdf](https://cdn.pfizer.com/pfizer.com/Pfizer_Health_Literacy_Position_Paper.pdf). Accessed 10/15/21. (last sentence)
7. Talking Points About Health Literacy. Centers for Disease Control and Prevention. Available at <https://www.cdc.gov/healthliteracy/shareinteract/TellOthers.html#:~:text=Nine%20out%20of%2010%20adults,than%20necessary%20morbidity%20and%20mortality>. Published 10/17/19. Accessed 10/7/21. (First point)
8. Health Literacy in Healthy People 2030. Health.gov. Available at <https://health.gov/our-work/national-health-initiatives/healthy-people/healthy-people-2030/health-literacy-healthy-people-2030>. Accessed 11/18/21. (Third section, first and second bullet points.)
9. History of Health Literacy Definitions. U.S. Department of Health and Human Services. Available at <https://health.gov/our-work/national-health-initiatives/healthy-people/healthy-people-2030/health-literacy-healthy-people-2030/history-health-literacy-definitions#:~:text=Earlier%20iterations%20of%20Healthy%20People,a%20new%20definition%3A%20%E2%80%9CHealth%20literacy>. Accessed 11/19/21. (Second paragraph, last sentence)
10. Via transcript of interview with Annlouise Assaf. [Empowering Patients by Closing the Health Literacy Gap](#). Accessed 10/7/21.
11. Why Raising Health Literate Children is Important. Pfizer. Available at <https://www.pfizer.com/news/hot-topics/why-raising-health-literate-children-is-important>. Accessed 10/7/21. (Last paragraph of 2nd section, quote from Andrews)
12. Translating Technical Language into Plain Language for Clinical Trials. Pfizer. Available at <https://www.pfizer.com/news/hot-topics/translating-technical-language-into-plain-language-for-clinical-trials>. Accessed 10/7/21.
13. Empowering Patients by Closing the Health Literacy Gap. Pfizer. Available at <https://www.pfizer.com/news/hot-topics/empowering-patients-by-closing-the-health-literacy-gap>. Accessed 10/7/21. (second bullet point)
14. Empowering Patients by Closing the Health Literacy Gap. Pfizer. Available at <https://www.pfizer.com/news/hot-topics/empowering-patients-by-closing-the-health-literacy-gap>. Accessed 10/7/21. (first bullet point)
15. Empowering Patients by Closing the Health Literacy Gap. Pfizer. Available at <https://www.pfizer.com/news/hot-topics/empowering-patients-by-closing-the-health-literacy-gap>. Accessed 10/7/21. (Paraphrased block quote by Annlouise)
16. Health Literacy: Learn to be Well. Pfizer. Available at: <https://www.pfizer.com/products/medicine-safety/health-literacy>. Accessed 10/7/21.
17. Ask Me 3: Good Questions for Your Good Health. Institute for Healthcare Improvement. Available at <http://www.ihl.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx>. Accessed 11/18/21.
18. Health Literacy: Learn to be Well. Pfizer. Available at: <https://www.pfizer.com/products/medicine-safety/health-literacy>. Accessed 10/7/21.
19. Andrews, Emma. Interview by Kate Silver. 10/19/21.
20. Health Literacy: Learn to be Well. Pfizer. Available at: <https://www.pfizer.com/products/medicine-safety/health-literacy>. Accessed 10/7/21.
21. Empowerment Through Patient Education: How to Play an Active Role in Your Healthcare. Pfizer.com. Available at <https://www.pfizer.com/news/hot-topics/empowerment-through-patient-education-how-to-play-an-active-role-in-your-healthcare>. Accessed 12/03/21. (first paragraph)
22. Empowerment Through Patient Education: How to Play an Active Role in Your Healthcare. Pfizer.com. Available at <https://www.pfizer.com/news/hot-topics/empowerment-through-patient-education-how-to-play-an-active-role-in-your-healthcare>. Accessed 12/03/21. (third paragraph).
23. Jewell, Patti and Zincone, Michael. Interview by Kate Silver. 9/29/21.
24. Empowerment Through Patient Education: How to Play an Active Role in Your Healthcare. Pfizer.com. Available at <https://www.pfizer.com/news/hot-topics/empowerment-through-patient-education-how-to-play-an-active-role-in-your-healthcare>. Accessed 12/03/21. (fifth paragraph)
25. Jewell, Patti and Zincone, Michael. Interview by Kate Silver. 9/29/21.
26. Jewell, Patti and Zincone, Michael. Interview by Kate Silver. 9/29/21.
27. Millions in U.S. Lost Someone Who Couldn't Afford Treatment. Gallup. Available at <https://news.gallup.com/poll/268094/millions-lost-someone-couldn-afford-treatment.aspx>. Published 11/12/19. Accessed 10/8/2021. (first two stats)
28. Could a Patient Assistance Program Help You? Pfizer. Available at <https://www.pfizer.com/node/543516>. Accessed 10/22/21. (paragraph 5)



29. Interview with Afryea Holland, 9/30/21.
30. Could a Patient Assistance Program Help You? Pfizer. Available at <https://www.pfizer.com/node/543516>. Accessed 10/22/21. (Last quote)
31. Pfizer RX Pathways, <https://www.pfizerrxpathways.com>.
32. Holland, Afryea. Interview by Kate Silver. 9/30/21.
33. Holland, Afryea. Interview by Kate Silver. 9/30/21.
34. Pfizer. How Wearable Technology is Helping Scientists Better Understand Patients and Diseases. Available at <https://www.pfizer.com/news/hot-topics/how-wearable-technology-is-helping-scientists-better-understand-patients-and-diseases>. Accessed 12/3/21. (first sentence second paragraph)
35. Pfizer. How Wearable Technology is Helping Scientists Better Understand Patients and Diseases. Available at <https://www.pfizer.com/news/hot-topics/how-wearable-technology-is-helping-scientists-better-understand-patients-and-diseases>. Accessed 12/3/21. (third paragraph)
36. National Eczema Association. What is Atopic Dermatitis? Available at [https://nationaleczema.org/eczema/types-of-eczema/atopic-dermatitis/?gclid=CjwKCAjwkvWKBhB4EiWA-GHjFuQuV5AYxXeebBEkyflMRBquErUIIbK0RA\\_Q88ONXieTkxC6We4V7RoCDc0QAvD\\_BwE](https://nationaleczema.org/eczema/types-of-eczema/atopic-dermatitis/?gclid=CjwKCAjwkvWKBhB4EiWA-GHjFuQuV5AYxXeebBEkyflMRBquErUIIbK0RA_Q88ONXieTkxC6We4V7RoCDc0QAvD_BwE). Accessed 10/06/21.
37. Pfizer. How Wearable Technology is Helping Scientists Better Understand Patients and Diseases. Available at <https://www.pfizer.com/news/hot-topics/how-wearable-technology-is-helping-scientists-better-understand-patients-and-diseases>. Accessed 12/3/21. (sixth paragraph)
38. Pfizer. How Wearable Technology is Helping Scientists Better Understand Patients and Diseases. Available at <https://www.pfizer.com/news/hot-topics/how-wearable-technology-is-helping-scientists-better-understand-patients-and-diseases>. Accessed 12/3/21. (last sentence)
39. Pfizer. How Wearable Technology is Helping Scientists Better Understand Patients and Diseases. Available at <https://www.pfizer.com/news/hot-topics/how-wearable-technology-is-helping-scientists-better-understand-patients-and-diseases>. Accessed 12/3/21. (fifth paragraph)
40. McCarthy, Tim. Interview by Kate Silver. 10/5/21.
41. Benefits of Telemedicine. Johns Hopkins Medicine. Available at <https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/benefits-of-telemedicine>. Accessed 10/11/21. (first paragraph)
42. Pfizer Launches Virtual Clinical Trial. BMJ. Available at <https://www.bmj.com/content/342/bmj.d3722>. Published 6/14/2011. Accessed 10/12/21.
43. Using Telehealth to Expand Access to Essential Health Services During the Covid-19 Pandemic. CDC. Available at <https://www.cdc.gov/coronavirus/2019-ncov/hcp/telehealth.html>. Published 6/10/2020. Accessed 10/12/21. (bulleted list)
44. Using Telehealth to Expand Access to Essential Health Services During the Covid-19 Pandemic. CDC. Available at <https://www.cdc.gov/coronavirus/2019-ncov/hcp/telehealth.html>. Published 6/10/2020. Accessed 10/16/21. (bullet #7)
45. What is Telehealth? Health Resources & Services Administration. Available at <https://www.telehealth.hhs.gov/patients/understanding-telehealth/>. Updated 8/16/2021. Accessed 10/12/21. (Benefits of telehealth section)
46. Preparing for a Virtual Visit. The United States Department of Health and Human Services. Available at: <https://telehealth.hhs.gov/patients/preparing-for-a-video-visit/>. Updated 7/2/21. Accessed 10/16/21. (“Preparing for your visit” bullet points 1, 2, 3, 4; “troubleshooting telehealth technology” bullet point 3)
47. Jewell, Patti and Zincone, Michael. Interview by Kate Silver. 9/29/21.
48. For Education, Support and Assistance, Patient Advocacy Groups Can Help. Pfizer. Available at <https://www.pfizer.com/news/hot-topics/for-education-support-and-assistance-patient-advocacy-groups-can-help>. Accessed 12/3/21. (paragraph 2)
49. For Education, Support and Assistance, Patient Advocacy Groups Can Help. Pfizer. Available at <https://www.pfizer.com/news/hot-topics/for-education-support-and-assistance-patient-advocacy-groups-can-help>. Accessed 12/3/21. (paragraph 5)
50. Jewell, Patti and Zincone, Michael. Interview by Kate Silver. 9/29/21.
51. Jewell, Patti and Zincone, Michael. Interview by Kate Silver. 10/18/21.
52. Pfizer Oncology Patient Centricity Ecosystem: From Launch to Impact. Pfizer. Available at <https://cdn.pfizer.com/pfizercom/Pfizer-APR-WhitePaper-080921.pdf>. Date 8/9/21. Accessed: 10/21/21. (summary from page 1, 2; “building programs” language in Patti’s quote on page 6)
53. Pfizer Oncology Patient Centricity Ecosystem: From Launch to Impact. Pfizer. Available at <https://cdn.pfizer.com/pfizercom/Pfizer-APR-WhitePaper-080921.pdf>. Date 8/9/21. Accessed: 10/21/21. (page 11, graphic)
54. Pfizer Oncology Patient Centricity Ecosystem: From Launch to Impact. Pfizer. Available at <https://cdn.pfizer.com/pfizercom/Pfizer-APR-WhitePaper-080921.pdf>. Date 8/9/21. Accessed: 10/21/21. (page 17, first paragraph)
55. Jewell, Patti and Zincone, Michael. Interview by Kate Silver. 9/29/21.

56. Andrews, Emma. Interview by Kate Silver. October 19, 2021.
57. Andrews, Emma. Interview by Kate Silver. October 19, 2021.
58. Anatomy of a Clinical Trial: The Purpose, People and Phases of Clinical Research. Pfizer. Available at [https://www.pfizer.com/news/hot-topics/anatomy\\_of\\_a\\_clinical\\_trial\\_the\\_purpose\\_people\\_and\\_phases\\_of\\_clinical\\_research](https://www.pfizer.com/news/hot-topics/anatomy_of_a_clinical_trial_the_purpose_people_and_phases_of_clinical_research). Accessed 12/3/21.
59. Anatomy of a Clinical Trial: The Purpose, People and Phases of Clinical Research. Pfizer. Available at [https://www.pfizer.com/news/hot-topics/anatomy\\_of\\_a\\_clinical\\_trial\\_the\\_purpose\\_people\\_and\\_phases\\_of\\_clinical\\_research](https://www.pfizer.com/news/hot-topics/anatomy_of_a_clinical_trial_the_purpose_people_and_phases_of_clinical_research). Accessed 12/3/21.
60. Anatomy of a Clinical Trial: The Purpose, People and Phases of Clinical Research. Pfizer. Available at [https://www.pfizer.com/news/hot-topics/anatomy\\_of\\_a\\_clinical\\_trial\\_the\\_purpose\\_people\\_and\\_phases\\_of\\_clinical\\_research](https://www.pfizer.com/news/hot-topics/anatomy_of_a_clinical_trial_the_purpose_people_and_phases_of_clinical_research). Accessed 12/3/21.
61. Anatomy of a Clinical Trial: The Purpose, People, and Phases of Clinical Research. Pfizer. Available at [https://www.pfizer.com/news/hot-topics/anatomy\\_of\\_a\\_clinical\\_trial\\_the\\_purpose\\_people\\_and\\_phases\\_of\\_clinical\\_research](https://www.pfizer.com/news/hot-topics/anatomy_of_a_clinical_trial_the_purpose_people_and_phases_of_clinical_research). Accessed 12/3/21.
62. Frequently Asked Questions. CISCRP.com. Available at <https://www.ciscrp.org/education-center/important-information>. Accessed 11/22/21. (“Why participate in a clinical trial?”)
63. How Patient Centricity Drives Innovation. Pfizer. Available at [https://www.pfizer.com/news/featured\\_stories/featured\\_stories\\_detail/how\\_patient\\_centricity\\_drives\\_innovation](https://www.pfizer.com/news/featured_stories/featured_stories_detail/how_patient_centricity_drives_innovation). Accessed 10/21/21. (paragraph 5 and 6)
64. Leventhal, David. Interview by Kate Silver. 11/22/21.
65. Leventhal, David. Interview by Kate Silver. 11/22/21.
66. Leventhal, David. Interview by Kate Silver. 11/22/21.
67. Translating Technical Language into Plain Language for Clinical Trials. Pfizer. Available at [https://www.pfizer.com/news/hot-topics/translating\\_technical\\_language\\_into\\_plain\\_language\\_for\\_clinical\\_trials](https://www.pfizer.com/news/hot-topics/translating_technical_language_into_plain_language_for_clinical_trials). Accessed 10/11/21.
68. Why Should I Participate in a Clinical Trial? National Institutes of Health. Available at <https://www.nih.gov/health-information/nih-clinical-research-trials-you/why-should-i-participate-clinical-trial>. Accessed 10/11/21. (fourth paragraph)
69. How Patient Centricity Drives Innovation. Pfizer. Available at [https://www.pfizer.com/news/featured\\_stories/featured\\_stories\\_detail/how\\_patient\\_centricity\\_drives\\_innovation](https://www.pfizer.com/news/featured_stories/featured_stories_detail/how_patient_centricity_drives_innovation). Accessed 10/11/21. (paragraph 6)
70. Anatomy of a Clinical Trial: The Purpose, People and Phases of Clinical Research. Pfizer. Available at [https://www.pfizer.com/news/hot-topics/anatomy\\_of\\_a\\_clinical\\_trial\\_the\\_purpose\\_people\\_and\\_phases\\_of\\_clinical\\_research](https://www.pfizer.com/news/hot-topics/anatomy_of_a_clinical_trial_the_purpose_people_and_phases_of_clinical_research). Accessed 12/3/21.
71. Questions to Ask Your Doctor About Treatment Clinical Trials. NIH National Cancer Institute. Available at <https://www.cancer.gov/about-cancer/treatment/clinical-trials/questions>. Accessed 10/11/21. (bullet points)
72. Protecting Your Safety & Privacy. Pfizer.com. Available at <https://www.pfizerclinicaltrials.com/about/protecting-your-safety-and-privacy#ParticipantRights>. Accessed 11/22/21.
73. Expanded Access and Compassionate Use. Pfizer.com. Available at <https://www.pfizer.com/science/clinical-trials/expanded-access>. Accessed 11.22.21. (section 2)

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