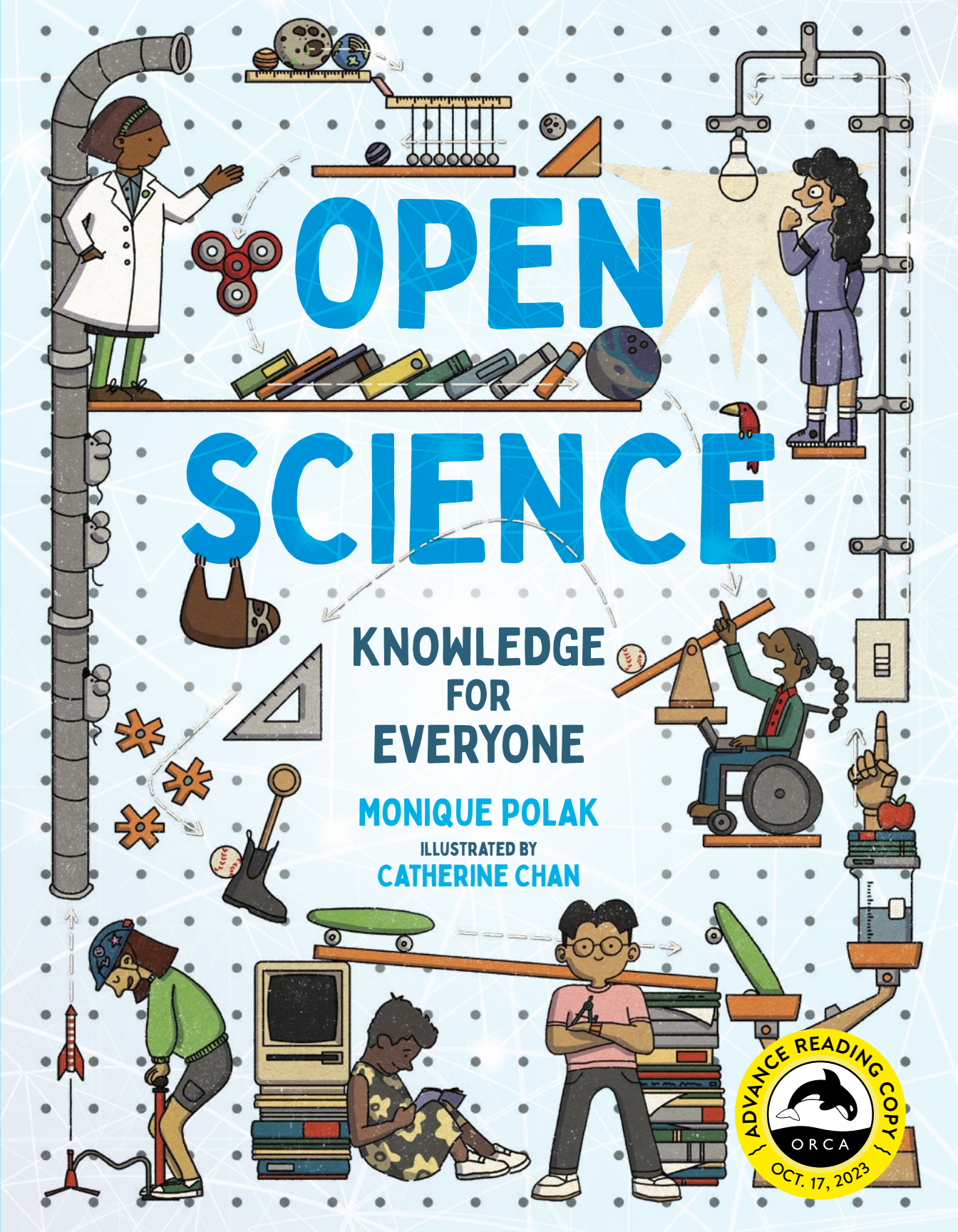

OPEN
SCIENCE
KNOWLEDGE
FOR
EVERYONE
MONIQUE POLAK
ILLUSTRATED BY
CATHERINE CHAN
ADVANCE READING COPY
ORCA
OCT. 17, 2023

KNOWLEDGE IS MEANT TO BE SHARED.

SCIENCE IS FOR EVERYONE, RIGHT? Unfortunately, that's not always true. Discovery, research and innovation are often kept top secret, and big businesses charge high prices for that information. The field of open science is trying to change that. Teams of scientists around the world are working together to improve and speed up scientific research and share their results so that everyone benefits.

Open Science: Knowledge for Everyone examines the history of scientific research and how ideas and information are shared and why. It also looks at innovations made using open science, such as treatments for diseases and vaccines to protect against viruses like COVID-19. Discover how to become a citizen scientist and what we all can do to share knowledge and make the world a better place.

This is an advance reading copy of the uncorrected proofs and is not for sale. Changes may be made to the text before publication, so **all quotations for review must be checked against the final bound book.**

MIDDLE READER NONFICTION • AGES 9–12
Publication: October 17, 2023

Final version will be a hardcover
9781459833586 HC • $26.95
9781459833593 PDF • 9781459833609 EPUB

ORCA BOOK PUBLISHERS
orcabook.com • 1-800-210-5277

For more information, contact Kennedy Cullen
1-800-210-5277 • kennedy@orcabook.com

ORCA Think

@orcabook

IVALUECANADIANSTORIES.CA

OPEN SCIENCE

KNOWLEDGE FOR EVERYONE

AUTHOR: **MONIQUE POLAK** ILLUSTRATOR: **CATHERINE CHAN** **October 17, 2023**

Part of the nonfiction Orca Think series for middle-grade readers, this illustrated book explores the concept of open science and how scientists around the world are working together to make research available to everyone.

FORMAT	Hardcover	PDF	EPUB
7 × 9"	9781459833586	9781459833593	9781459833609
96 pages	$26.95		

KEY SELLING POINTS

- A primer on the history of science, how research and discovery were and are managed and what the field of open science is doing to make knowledge and innovation available to everyone.
- Introduces STEM concepts, such as the scientific method, user innovation, citizen science and how kids can get involved.
- *Open Science: Knowledge for Everyone* addresses issues of equity, diversity and inclusion in innovation and research in the sciences.
- The world's first open science institution is in Montreal, and UNESCO has recently endorsed the concept of open science. Guy Rouleau, the director of The Neuro and co-founder of the Tanenbaum Open Science Institute, was the expert reader of the text.
- The development of the COVID-19 vaccine is one of the best examples of open science at work, where teams of scientists around the world collaborated to create a vaccine in record time.

ABOUT THE AUTHOR

PHOTO CREDIT: JOHN FREDERICK

MONIQUE POLAK is the author of over 30 books for young people. She is a three-time winner of the Quebec Writers' Federation Prize for Children's and YA Literature, now called the Janet Savage Blachford Prize. Monique taught for 35 years at Marianopolis College in Montreal. Her previous nonfiction titles include *I Am a Feminist: Claiming the F-Word in Turbulent Times* and *Why Humans Work: How Jobs Shape Our Lives and Our World*.

ABOUT THE ILLUSTRATOR

PHOTO CREDIT: TONY YIU

CATHERINE CHAN is a Toronto-based illustrator with a previous life in project management and technology. Her work explores her relationships as an immigrant, a mother and a lifelong learner, and acts as both self-exploration and self-declaration. She is excited about telling unique and inspiring stories through her illustrations.

PROMOTIONAL PLANS INCLUDE

- Print and online advertising campaigns
- Promotion at national and regional school, library and trade conferences
- Extensive ARC distribution, including NetGalley
- Blog and social media promotion
- Outreach in Orca newsletters

BISACS

JNF051170 JUVENILE NONFICTION / Science & Nature / Discoveries
JNF051190 JUVENILE NONFICTION / Science & Nature / History of Science
JNF051110 JUVENILE NONFICTION / Science & Nature / Experiments & Projects
JNF053200 JUVENILE NONFICTION / Social Topics / Values & Virtues

RIGHTS

Worldwide

AGES

9–12

ORCA Think

What's the big idea? Orca Think introduces us to the issues making headlines in the world today. It encourages us to question, connect and take action for a better future. With those tools we can all become better citizens. Now that's smart thinking!

PUBLICITY

For more information or a review copy,
please contact Kennedy Cullen at kennedy@orcabook.com

Order online at orcabook.com or orders@orcabook.com or 1-800-210-5277

ORCA BOOK PUBLISHERS
orcabook.com • 1-800-210-5277

@orcabook


OPEN
SCIENCE

ORCA Think

Question, connect and take action to become better citizens with a brighter future. Now that's smart thinking!

OPEN SCIENCE

KNOWLEDGE FOR EVERYONE

MONIQUE POLAK

ILLUSTRATED BY
CATHERINE CHAN

ORCA BOOK PUBLISHERS

Published in Canada and the United States
in 2023 by Orca Book Publishers.
orcabook.com

Library and Archives Canada Cataloguing in Publication
Title: Open science : knowledge for everyone / Monique Polak ; illustrated by Catherine Chan.
Names: Polak, Monique, author. | Chan, Catherine (Illustrator), illustrator.
Series: Orca think ; 11.
Description: Series statement: Orca think ; 11 | Includes bibliographical references and index.
Identifiers: Canadiana (print) 2022048158X | Canadiana (ebook) 2022048161X | ISBN 9781459833586 (hardcover) | ISBN 9781459833609 (EPUB) | ISBN 9781459833593 (PDF)
Subjects: LCSH: Science—Juvenile literature. | LCSH: Open scholarship—Juvenile literature.
Classification: LCC Q163 .P65 2023 | DDC j500—dc23

Library of Congress Control Number: 2022950920

Summary: Part of the nonfiction Orca Think series for middle-grade readers, this book explores the concept of open science and how scientists around the world are working together to make research available to everyone

Orca Book Publishers is committed to reducing the consumption of nonrenewable resources in the production of our books. We make every effort to use materials that support a sustainable future.

Orca Book Publishers gratefully acknowledges the support for its publishing programs provided by the following agencies: the Government of Canada, the Canada Council for the Arts and the Province of British Columbia through the BC Arts Council and the Book Publishing Tax Credit.

Cover and interior artwork by Catherine Chan
Edited by Kirstie Hudson
Design by Troy Cunningham
DNA spirals: Jimny Lova/Vecteezy.com
Molecular structures: PRAMOTE LERTNITIVAN/Vecteezy.com

Printed and bound in the United States.

26 25 24 23 • 1 2 3 4

To Guy Rouleau, who makes me happy
and introduced me to open science

Contents

INTRODUCTION

WHAT IS OPEN SCIENCE ANYHOW?

You've heard the words *open* and ***science***, but this may be the first time you have heard them used together. The word *science* comes from the Latin *scientia*, which means knowledge. Science is a way of gaining knowledge about the world through observation and experimentation. The words *open* and *closed* don't need much explaining. If a store is open, we can go in. If it's closed, we'll have to come back another time.

When I hear the word *open*, I always think of the phrase *open sesame.* When I was a kid, we'd say, "Open sesame" if we hoped to get into someplace special—like a neighbor's tree house. *Open sesame* were the magical words uttered in the story *One Thousand and One Nights* when Ali Baba and the 40 thieves wanted to enter the cave where secret treasure was hidden.

In stories and paintings, open doors often represent freedom and possibility. The school where I taught for many years has an open-door policy, meaning students can drop in at their teachers' offices to ask questions.

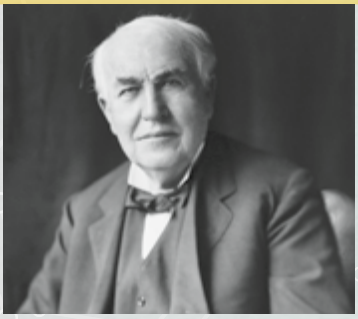
Sometimes a password is required. That was the case for Ali Baba and his thieves.

ZU_09/GETTY IMAGES

CLOSED-DOOR POLICY

Keeping things secret and controlling information has long been part of the world of science. Here are some ways in which science, even today, remains closed:

- X Scientists focused on advancing their own careers, and on being the first to make a discovery or come up with a cure, may be reluctant to share their findings with others.
- X Subscriptions to most scientific journals are so expensive that some scientists, especially those in developing countries, cannot afford them.
- X Patents (you will learn about them in chapter 2) often prevent scientists from sharing their findings.
- X Even universities, where much scientific research is done, still hope for windfall discoveries (you will learn about windfalls in chapter 2) and may prefer not to share their researchers' findings.



Inventor Thomas Edison worked alone, competing with other inventors of his time.

EVERETT COLLECTION/SHUTTERSTOCK

SCIENCE MATTERS

The term *open science* was first used in the late 1990s. Here's the commonly accepted definition: "Open science refers to the open sharing of data and reagents." Data is information, and reagents are material discoveries we can see and touch (for example, a solution for growing cells).

The term *closed* is less positive.

Though we sometimes have to close our doors—for instance, if your kid sister is making too much noise down the hall—closed doors often have a negative connotation. When we talk about doors being closed to certain people, we are referring to a lack of possibility or opportunity.

You're probably wondering what the words *open* and *closed* have to do with science.

The answer is *a lot*.

Until recently the world of science was largely *closed*. Most scientific discoveries were made by individual people or small groups. Take, for example, Thomas Edison, who, in 1879, invented the light bulb at his laboratory in New Jersey. Or scientists Frederick Banting and Charles Best, who, in 1921, discovered insulin as a treatment for diabetes, a disease that had until then been considered fatal. (Interestingly, the first person to receive an insulin injection was a 14-year-old boy named Leonard Thompson.)

It was hard for early scientists to share their findings. For one thing, there was no internet! In science's early days, scientists shared their discoveries by writing letters to one another. This system led to the development of ***scientific journals***, which to this day still play an important role in the spread of scientific information.

But only some people had access to these journals, which remains the case today too. This is only one of many ways in

SCIENCE MATTERS

Researchers have identified three main motives for sharing—fairness, merit and benevolence. It would be fair if six kids each got one-sixth of a pizza. An example of merit would be rewarding the kids who completed their chores with slightly larger slices of pizza. An example of benevolence would be offering your pizza slice to a kid whose family cannot afford treats like store-bought pizza.

which the doors to science have been—and remain—closed to many people.

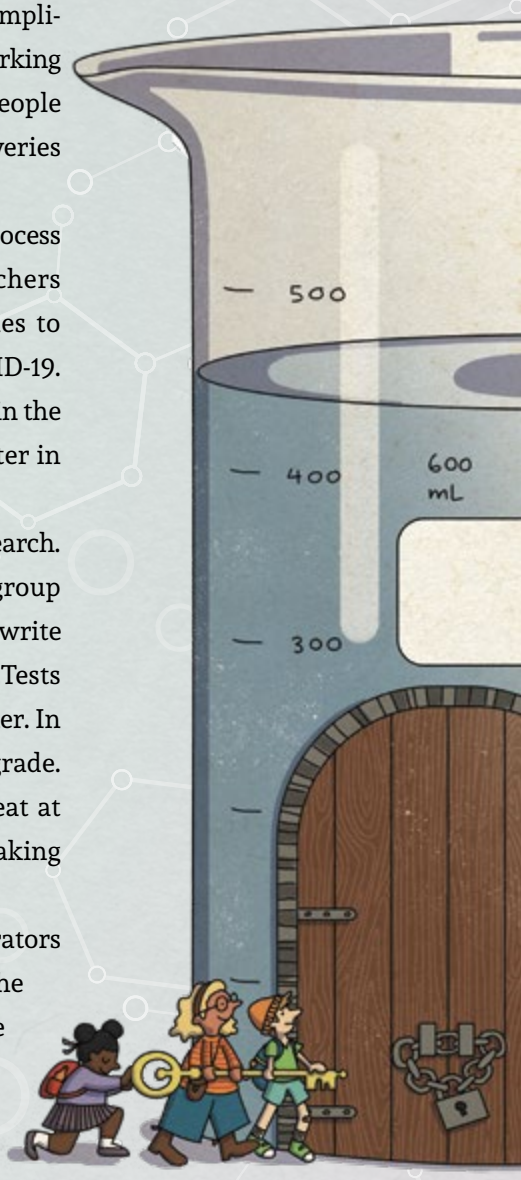
Of course, science has changed a lot over time, and it keeps changing. Scientific discoveries have become more complicated. Nowadays it usually takes large teams of people working in different fields to make discoveries. When these people work together and openly share their findings, discoveries can be made more quickly.

The best example of collaboration to speed up the process of discovery is how scientists and medical researchers around the world came together to produce vaccines to protect us from the SARS-CoV-2 virus that causes COVID-19. Their collaboration marked such an important change in the way science is done that it will get its own chapter later in this book.

Open scientists openly share the results of their research.

Think of it this way: ***open science*** is like doing a group project for school instead of writing a test. When you write a test, you hope to get the highest mark in the class. Tests are a competition, with students pitted against each other. In a group project, students work together for a shared grade. Different kids have different strengths. Some are great at taking notes, others at making charts and some at speaking in front of the class.

The same is true in open science. Different collaborators bring their individual strengths to a project—and in the end, the results are usually better and arrived at more quickly than if one person had done all the work.



MANY BRANCHES

SCIENCE IS LIKE A TREE WITH MANY BRANCHES.
JUST HOW MANY DEPENDS ON HOW YOU COUNT THEM.

MANY PEOPLE SAY SCIENCE HAS
THE FOLLOWING FIVE MAIN BRANCHES:

CHEMISTRY:
the study of matter and how matter changes

PHYSICS:
the study of energy and matter and how the two interact

GEOLOGY:
the study of the earth's structure

ASTRONOMY:
the study of the stars and the universe

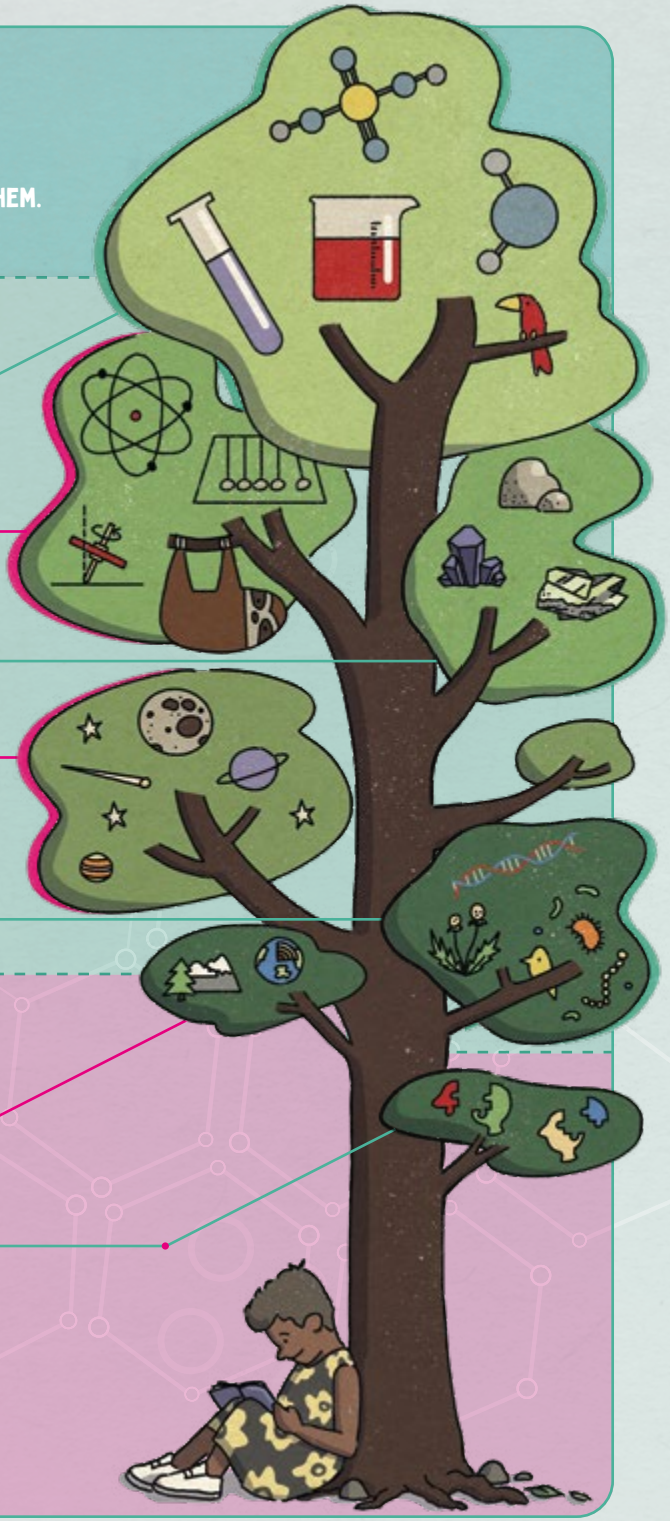
BIOLOGY:
the study of life

OTHERS SAY SCIENCE HAS SEVEN BRANCHES,
ADDING THESE TWO TO THE LIST:

ECOLOGY:
the study of the connections between organisms and their environments

PSYCHOLOGY:
the study of human behavior

OTHERS BELIEVE
SCIENCE HAS 15 BRANCHES—
AND SOME SAY IT HAS
AS MANY AS 50!



As the ancient Greek philosopher Aristotle observed, "The whole is greater than the sum of its parts."

Open science also lets more people—no matter their gender, race or where they live or go to school—participate in the discovery process. As you will see, even kids can contribute to open science!

In many ways, this book is about sharing. Open scientists freely share their findings without asking for anything in exchange. As most kids know, sharing does not always come naturally. You may not always be in the mood to share a new book—or the last slice of pizza.

Sharing sometimes means having to let go of something. Sharing is a learned behavior that helps us develop life skills such as the ability to cooperate with others. Sharing is also a way to show others that we care about them, that life isn't only about us!

I interviewed many people for this book. My favorite quote about open science comes from Katie Corker, a psychology professor at Grand Valley State University in Michigan: "Open science is not just a T-shirt you can wear. Open science is a behavior!"

Many people are surprised to learn that open science is not common practice in the world of science. Closed science has been the norm, and it continues to be the norm in many laboratories around the world. To understand why, let's look at the history of science.

These students are working collaboratively on a group project. Group members bring different strengths to a shared project.

FATCAMERA/GETTY IMAGES

PHILANTHROPISTS SUPPORT OPEN SCIENCE

Philanthropists are people who donate money to good causes. These causes include scientific research that could lead to new treatments or cures for diseases. More and more philanthropists who support scientific research also support open science. They want to know that any research they fund will be shared openly, to speed up discovery and help as many people as possible.

In 2021, Toronto businessman Larry Tanenbaum, his wife, Judith, and their family made a major donation to the University of Calgary's Hotchkiss Brain Institute (HBI). The Tanenbaums wanted to show their support for the HBI's decision to adopt the open-science approach.

Larry Tanenbaum understands that open science is transforming the world of scientific research. "Open science allows researchers to share both their successes and failures," he said. Tanenbaum, co-owner of the Toronto Maple Leafs, the Toronto Raptors and the Toronto Argonauts, sees a link between sports and open science. "Teamwork is powerful. The aspect of sharing information is also powerful," he said.

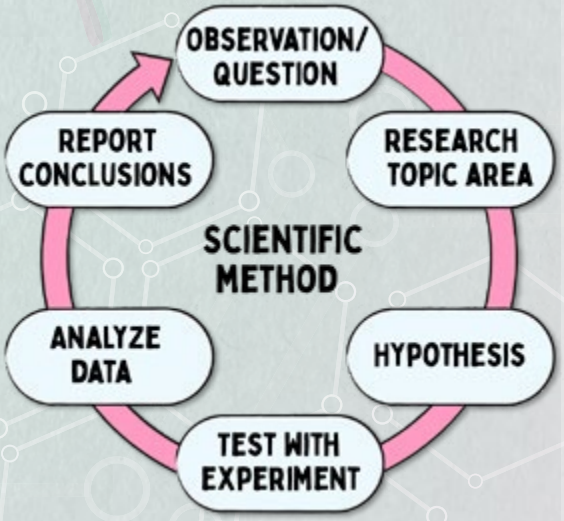
ONE

GET SET! GO!

THINKING LIKE A SCIENTIST

The process of observation and experimentation is known as the ***scientific method***. Asking a question is the first step. It takes curiosity to come up with a question. Luckily, being curious is human nature. How could we learn anything if we didn't ask questions?

It is also human to observe and then come up with a theory, which in the world of science is called a ***hypothesis***. To check whether our hypothesis is correct, we must collect information and run experiments. Then we need to analyze our findings and, if necessary, modify or change our hypothesis. Only then can we present a scientific conclusion. Even when we do, our findings need to be retested to ensure that they and our



ADAPTED FROM EFBRAZIL/WIKIMEDIA COMMONS/CC BY-SA 4.0

PATRONS LIVE ON

You've probably heard of the Nobel Prizes. Since 1901 five Nobel Prizes have been awarded every year, in five categories. Three of those categories (physics, chemistry, and physiology or medicine) are related to science. The other two Nobel Prizes are for literature and peace. Scientists who have won a Nobel Prize include Marie Curie, Pierre Curie and Henri Becquerel, who together won the Nobel Prize in Physics in 1903, and Albert Einstein, who won the Nobel Prize in Physics in 1921.

There's a connection between the Nobel Prize and the old system of patrons. Back in Galileo Galilei's time, scientists were sometimes rewarded with gold medals featuring engraved likenesses of their patrons. The Nobel Prize is a gold medal—and on it is the likeness of Alfred Nobel, the Swedish chemist who invented dynamite and left his fortune to create the Nobel Institute, which funds the Nobel Prizes.

TRAVELER1116/GETTY IMAGES

Charles Best was a 21-year-old medical student when, in 1921, he began working with Frederick Banting, who was already an accomplished surgeon and professor.

THOMAS FISHER RARE BOOK LIBRARY, UOFT/ FLICKR.COM/CC BY-SA 2.0

conclusion are correct. In the world of science, this retesting is usually done by other scientists.

CURIOSITY'S COOL

If you're like me, you're curious about everything! Here's an example. At 7:03 a.m. today those of us living in southern Quebec (which includes the city of Montreal) observed a strange rumbling. Like everyone else who felt the rumbling, my boyfriend and I were curious to know what had caused it. He hypothesized that perhaps the rumbling was caused by trucks going by or an airplane overhead. In order to test that hypothesis, we looked out the window, but there was no truck or airplane. So we did what many curious people do nowadays—we turned to Google! That's how we learned that within minutes of the event, ***seismologists*** at Earthquakes Canada had determined we'd experienced a magnitude 3.9 earthquake—not strong enough to cause damage, but strong enough to have awakened many Quebecers.

MEET IMHOTEP, THE FATHER OF MEDICINE

As you have already learned, science has many branches. In this book we will focus mostly on the world of medicine, also known as health science. Just as Banting and Best came up with a lifesaving treatment for diabetes, the hope is that the widespread adoption of open science will speed up the

The *Edwin Smith Surgical Papyrus* is believed to be the world's oldest medical text.

MAIN: JEFF DAHL/WIKIMEDIA COMMONS/ PUBLIC DOMAIN

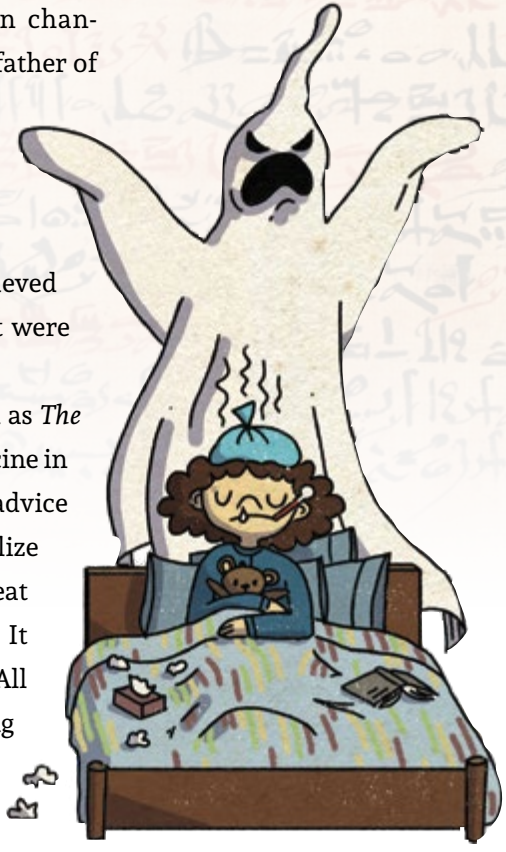
INSET: DAVE PRIMOV/DREAMSTIME.COM

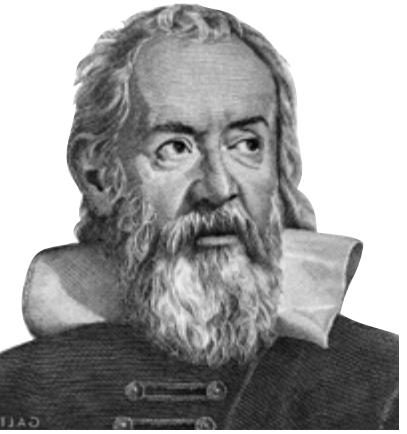
discovery of treatments for the many diseases plaguing humanity—everything from cancers to neurological diseases such as ***Alzheimer's***.

Many people consider Imhotep, an Egyptian chancellor who lived in the 27th century BCE, to be the father of medicine. Imhotep was one busy guy—he is also believed to have been the first engineer and architect. As if that weren't enough, Imhotep was a philosopher too.

Until Imhotep's time, ancient Egyptians believed in magical cures for illnesses, which they thought were caused by demons or angry ghosts.

Imhotep was the author of what is now known as *The Edwin Smith Surgical Papyrus*, which describes medicine in the ancient Nile Valley. The text is full of practical advice such as how to close wounds with stitches, immobilize patients with head and spinal cord injuries, and treat certain skin diseases with a plant called aloe vera. It even includes a section on treating crocodile bites! All these discoveries came from asking questions, coming up with hypotheses and testing those hypotheses.





It is believed that Galileo Galilei was the first person to use a telescope to look into space.

PRACHAYA ROEKDEETHAWEESAB/ SHUTTERSTOCK.COM

PATRONS FOOT THE BILL FOR EARLY SCIENCE

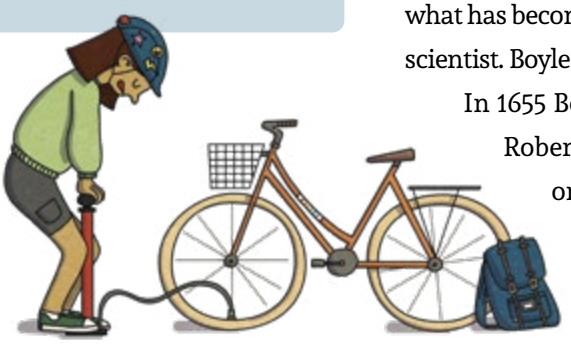
In today's world, scientists work in university laboratories, at government agencies or for businesses such as drug-development companies. But that wasn't always the case.

In the 16th and 17th centuries, many scientists had patrons. These patrons were generally powerful political or religious figures who funded the work of scientists. You may have heard of Galileo Galilei, the Italian astronomer who discovered the four largest moons of Jupiter and the stars of the Milky Way. He would likely not have made these discoveries were it not for the Medici family, who were his patrons. Galileo met the family in 1605, when he was hired to tutor Cosimo de' Medici in math.

Johannes Kepler, the German astronomer and mathematician who discovered the laws of planetary motion, had several patrons, including Holy Roman Emperor Rudolph II and Albrecht von Wallenstein, a Bohemian military leader and statesman.

SCIENCE MATTERS

Boyle's law states that the pressure of a gas increases as the volume of the container decreases, and vice versa. Every time you fill your bike tire, you see Boyle's law in action. As you pump air into the tire, the gas molecules inside become compressed and the pressure of the gas increases, pushing against the walls of the tire.



A HOBBY FOR RICH GUYS

There were also ***gentlemen scientists***, men who were wealthy enough that they could observe and do experiments in their spare time, kind of like a hobby. Robert Boyle, who discovered what has become known as Boyle's law, was an Irish gentleman scientist. Boyle was born into a wealthy family.

In 1655 Boyle hired a British university student named Robert Hooke to work as his assistant. Hooke went on to discover the law of elasticity and is the first person to have used the biological term ***cell***.

Hooke also worked as a surveyor for the City of London. And although Galileo and

Kepler had patrons, they also needed to earn some extra money. Galileo sold telescopes, and Kepler published horoscopes.

In the 18th and 19th centuries, governments began to sponsor prizes for scientific research, and universities began to hire professors to carry out scientific investigations.

SCIENCE MATTERS

Hooke's law—aka the law of elasticity—states that the force needed to extend a spring is related to the distance the spring is stretched. Here's an example. Balloons are elastic. When you blow air into a balloon, it expands. If your balloon bursts, the air empties out, and your balloon shrinks back to its original size.

SNAIL MAIL PLAYS A ROLE

In those early days of science, sharing discoveries was difficult and slow. In the 17th century handwritten letters were the most common way to share scientific information. Letters were inexpensive and, at the time, considered quick. A letter could be sent and received just about anywhere in Europe within a few weeks.

With more and more scientific letters going around, it became necessary to compile and share these letters and the information they contained. Henry Oldenburg was one of the first editors to take on this task. His published correspondence included over 3,000 letters between scientists—and that was only letters published between 1641 and 1677.

Oldenburg was the first secretary of the Royal Society, a scientific academy established in 1660. The society's motto was *Nullius in verba*—Latin for "Take nobody's word for it"—and proves that Oldenburg and his fellows at the Royal Society understood the importance of verifying the results of scientific experiments. In 1665 the Royal Society published Robert Hooke's book *Micrographia*, in which Hooke included illustrations of specimens he had studied using microscopes he designed.

An illustration of a microscope designed by Robert Hooke.

J J OSUNA CABALLERO/ SHUTTERSTOCK.COM

THE ROYAL SOCIETY/WIKIMEDIA COMMONS/ PUBLIC DOMAIN

SCIENTIFIC JOURNALS SPREAD LIKE MUSHROOMS

It was the work of people like Oldenburg and groups like the Royal Society that led to the development of scientific journals—***periodicals*** that let scientists report on their research and findings.

By 1800 there were about 30 scientific and medical journals. By 1900 that number had grown to about 700. Since then the number has mushroomed. It is estimated that there are more than 20,000 scientific journals today!

Scientific journals have a lot of influence. Today scientists' careers are based, in large part, on their publications—and on where their work is published. In the field of biology, the journals *Cell*, *Nature* and *Science* are so prestigious they are often sometimes referred to simply as *CNS*. Scientists who publish in *CNS* are rewarded with jobs, promotions and funding for their research.

The Chinese Academy of Sciences goes even further. The academy, which brings together scientists from all over China, is so eager to see its scientists' work appear in *CNS* that it gives financial bonuses to those who have work published. These scientists get paid about $30,000—equal to a year's salary.

THE ROYAL SOCIETY

SCIENCE MATTERS

The Royal Society's *Philosophical Transactions*, launched in 1665 and published and edited by Oldenburg, was the world's first scientific journal. The journal came out once a month and was sold for one shilling. Oldenburg's goal was to promote science and earn some money on the side. *Philosophical Transactions* continues to be published to this day.

SPLASHY SELLS

Critics of top-tier scientific journals such as *CNS* point out that these journals do not always publish the best research. Instead editors may favour splashy research—stories that will attract attention and go big around the world. Who doesn't want to read about a miracle cure or a newly discovered mammal?

In a few cases, research published in these journals has been proven incorrect. In 2006 the journal *Science* retracted two papers by Hwang Woo-suk, a South Korean scientist who claimed to have produced a stem-cell line from a cloned human embryo—that he and his team had injected genetic material from adult human cells into a human egg from which the ***DNA*** had been removed. Had the papers been true, it would have meant that cloning humans is possible.

Hwang Woo-suk apologized publicly, asking South Koreans for their forgiveness. He said the fabrications were done without his knowledge by scientists on his team.

South Korean scientist Hwang Woo-suk had to apologize for publishing fraudulent research done by scientists on his team.

CHUNG SUNG-JUN/GETTY IMAGES

SPOT THE DIFFERENCE

ANSWERS, PAGE 82

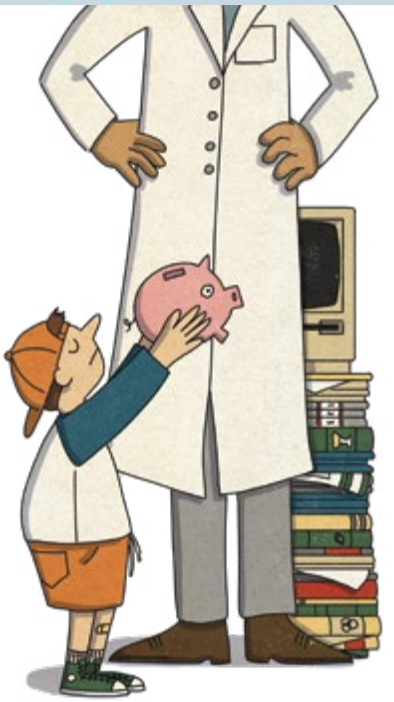
THE REPRODUCIBILITY PROJECT

Brian Nosek does science about science! To prove that scientific research is accurate, other scientists must be able to reproduce it. That's why, in 2011, Nosek and his team at the Center for Open Science, based in Charlottesville, Virginia, set up the Reproducibility Project. Their goal was to replicate the results of 100 psychological experiments published in respected journals in 2008. And guess what? Only 36 of the 100 replications showed results that were statistically significant (shown to be reliable and not a matter of chance).

Nosek believes the scientific process must be transparent, that other scientists—and the rest of us too—must be able to see how scientists make their discoveries. For us to take scientific research seriously, we need to know what methods were used and see the data that was produced. Nosek puts it this way: "We need to be able to debate about the evidence and the conclusions."

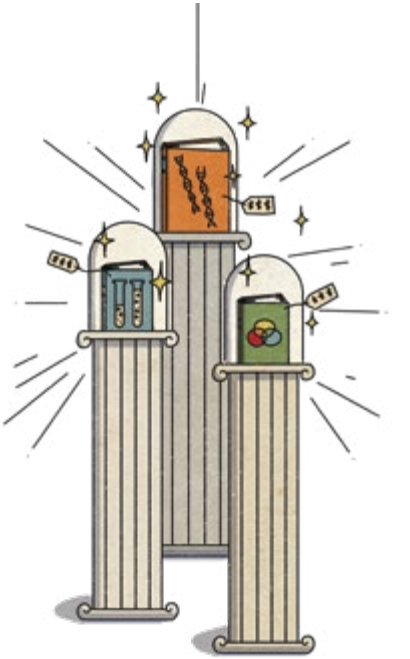
SCIENCE MATTERS

The term *open access* refers to the free, wide and open sharing of published work. This information can be read, downloaded and distributed to others. Shouldn't the latest, most accurate scientific research be freely available to us all? It's an easy question for those who believe in open science. And the answer is yes!



HIGH-COST SUBSCRIPTIONS

Most scientific and medical journals are not open. To read articles in most scientific journals, you need a subscription. Since subscriptions to these journals are usually expensive—in 2009 the University of Michigan spent over $2 million on subscriptions to scientific journals—people who do not have much money or are not affiliated with a university that can cover subscription costs lack ***open access*** to the latest research. To make matters worse, scientists who wish to publish in these journals have to pay hefty fees. With publishers earning money from both subscribers and contributors, scientific and medical journals have become big business. In 2019 Elsevier, one of the world's largest publishers of scientific and medical journals, made US$9.8 billion.



LIMITED-EDITION SCIENCE

In 2013, the day before he won the Nobel Prize in Physiology or Medicine, American biologist Randy Schekman published an article in *The Guardian* titled "How Journals Like *Nature*, *Cell* and *Science* Are Damaging Science." In his article, Schekman called these publications "luxury journals" and compared them to "fashion designers who create limited-edition handbags." Schekman went on to declare a boycott against *CNS*, saying his lab at University of California, Berkeley would no longer submit papers to *CNS*. At the time, and until 2019, Schekman was also editor of *eLife*, an open-access journal.

GIVING MORE PEOPLE ACCESS TO THE LATEST RESEARCH

In 2001 Harold Varmus, a Nobel Prize–winning scientist, co-founded the Public Library of Science (PLOS) as a way to open up the world of science publishing. PLOS does not believe in paper copies or expensive subscriptions. It uses the internet to spread science. "We want the latest scientific articles to be free for everyone to access and use," explained Dan Morgan, director of community and communications at PLOS.

In the PLOS model, articles are free to read, but it costs money to publish them. Once an article is accepted by the library, the author pays a fee called an ***article processing charge (APC)***. The APC, which runs between $1,000 and $5,000, is usually paid for by the university with which the scientist is affiliated. The system isn't perfect. "Three thousand dollars means a heck of a lot of money in places like sub-Saharan Africa," explained Morgan. "The model doesn't work as well in lower-funded economies or disciplines." To help solve that problem, PLOS introduced a system of waivers designed to help scientists at universities that cannot afford to pay an APC.

(TOP) NIH HISTORY OFFICE/WIKIMEDIA COMMONS/PUBLIC DOMAIN

(BOTTOM) JUNEBUG CLARK

NOT ONLY FOR GROWN-UPS

Some open-access scientific journals are for kids. *Frontiers for Young Minds* educates kids about science and gets them involved in science publishing. Scientists use kid-friendly language to write either about scientific concepts or their latest discoveries. Then kids aged 8 to 15 get involved, working with a mentor to review the articles. "We're educating the scientists of tomorrow to think critically in ways they can use for the rest of their lives," explained Laura Henderson, head of the public outreach program for *Frontiers for Young Minds*. Launched in 2013, the journal, available free of charge to anyone with an internet connection, had over 20 million hits and downloads at the time I interviewed Henderson in June 2022. Scientists Rob Knight and Einat Segev founded the journal. "Research is all well and good, but they thought if the person—or the child—on the street cannot understand the research that has been done, how can we make global change?" said Henderson.

Fourteen-year-old Saif, who lives in the United Arab Emirates, was one of four students who reviewed an article co-authored by scientists Élise Beaudin and Annalisa Bracco about the impact of marine heat waves on oceans. The students learned that heat waves don't happen only on land—they happen in water too. Marine heat waves can force fish, whales and sea turtles to migrate to cooler parts of the ocean. Coral cannot relocate, so the survival of sea creatures who live in coral reefs is jeopardized. Beaudin and Bracco recommend the creation of marine protected areas, where human activities like fishing would be banned, to give sea creatures a place to recover following a marine heat wave.

Thanks to his experience, Saif is hooked on science. "Science is something that gives the world power to change," he said.

TWO

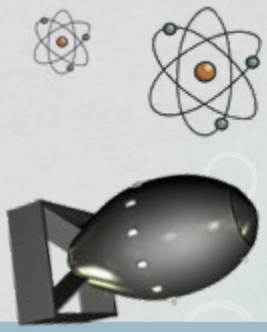
BIG SCIENCE IS BIG BUSINESS

MONEY MATTERS

Even if you do not care much about money or material things, there is no denying that money matters. Perhaps you get a weekly allowance. When you are older, you will need money to pay your bills. Nations collect taxes in order to provide services to citizens. These services include everything from highways to healthcare. Our tax dollars also help fund universities where, as you have already learned, a lot of scientific research takes place. So in large part, it's actually we citizens who pay for the creation and dissemination of scientific knowledge.

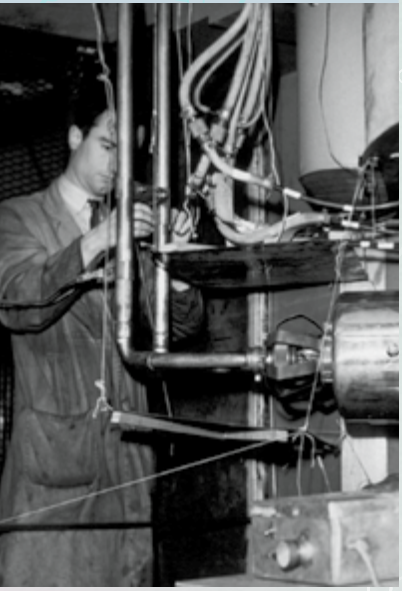
When developing new drugs for the pharmaceutical industry, scientists often work together as a team.
SKYNESHER/GETTY IMAGES

Galileo Galilei's scientific research was funded by the Medicis. Robert Boyle had family money. In their days, science was not yet big business.



SCIENCE MATTERS

Nuclear fission is the splitting of an atom into smaller atoms. A lot of energy is released during this process. When the energy is released gradually, it can be used to generate electricity. If the energy is released all at once, it can cause an explosion—like a bomb.



A scientist affiliated with the Manhattan Project, one of the world's most famous government-funded research projects.

JAMESBENET/GETTY IMAGES

SCIENCE GOES BIG

Science historians use the term ***big science*** to describe changes that occurred in the world of science in industrialized nations during and after World War II. Around that time governments and sometimes groups of governments began spending a lot of money on large scientific projects. Many of these projects had to do with the war.

The Manhattan Project was the code name for a research project that led to the development of the first atomic bombs. In the 1930s nuclear physicists around the world were experimenting with nuclear fission.

In 1939 physicist Albert Einstein, one of the most famous scientists ever, wrote to US president Franklin D. Roosevelt, urging him to get American scientists to create a nuclear bomb before Germany did. It is estimated that the US government spent a whopping $2 billion on the Manhattan Project!

Much of the early research for this project took place at Columbia University, in Manhattan, New York. But it wasn't only US scientists who worked on the Manhattan Project. The United Kingdom and Canada got involved too. In 1945 the American army attacked the Japanese cities of Hiroshima and Nagasaki with nuclear bombs. The use of those bombs remains controversial. Though the bombings of Hiroshima and Nagasaki may have helped end World War II for the the United States and its allies, many innocent lives were lost. It is estimated that more than 200,000 people—mostly civilians—were killed by those bombs. Many others later developed diseases such as leukemia, a form of cancer that can be caused by radiation exposure.

The invention of the atomic bomb changed world history. But many other scientific inventions also changed our lives—and showed the world that science could be big business.

PHILO FILES FOR A PATENT

In its own way, the invention of the television also changed our lives. Before the internet came along, families gathered around the television to watch their favorite shows. One of the earliest televisions was invented in 1927 by Philo Taylor Farnsworth. The screen on his image dissector was the size of a stamp. Farnsworth did what scientists and inventors did in his day—and what they still do today. He filed or applied for a ***patent*** for his invention.

NOT ALL INVENTORS ARE OLD

Even as a kid, Philo Taylor Farnsworth loved science. Farnsworth, who grew up in Utah, spent the first 12 years of his life living in a log cabin without electricity. When he was in high school, Farnsworth found a way to convert his family's home appliances to electric power. He also invented a tamperproof lock that won a national prize. While taking high school chemistry, Farnsworth came up with the idea of a vacuum tube. At age 21, using his vacuum tube, Farnsworth invented one of the first TVs. His first TV patent was granted by the US government in 1930. Later in life Farnsworth did research in the field of nuclear fission.

SPECIAL COLLECTIONS, J. WILLARD MARRIOTT LIBRARY, THE UNIVERSITY OF UTAH

Let's say you and your buddy invent a brand-new kind of lemonade—say, one that's banana-flavored. Customers from all over your neighborhood flock to your lemonade stand. You and your buddy are busy all day, making and selling lemonade. But how can you ensure that other kids do not get their hands on your secret recipe? A patent helps protect your invention.

Patents protect inventors—and some patents have made inventors rich. There might, for example, be kids out there who would pay for your lemonade recipe!

THE PROBLEM WITH PATENTS

There are downsides to patents. Since patents are designed to stop others from using an invention, they can prevent open sharing. Patents can also slow down discovery. This is an especially serious problem in the world of medicine. Patients with terrible and sometimes life-threatening or fatal illnesses do not have time to waste. We need cures now for diseases such as cancer as well as for neurological or brain diseases like Alzheimer's and amyotrophic lateral sclerosis (ALS), also called Lou Gehrig's disease after the baseball player who had it. A five-year delay in finding a treatment to prevent dementia means another 50 million people worldwide will develop this disease.

SCIENCE MATTERS

For every 3,000 Canadian university patents, only one new company is formed. In the United States, only 1/10th of 1 percent of approximately 400,000 annual start-up companies are spun off from college or university patents.

DREAMING OF WINDFALLS

In the 1990s the Canadian government was searching for new ways to help pay for medical research at universities. The government decided to encourage universities to apply for more patents. It and the universities hoped that by doing so, they would end up with a *windfall*—which means a pile of cash!

Universities and pharmaceutical companies believe in patents. The research conducted in university laboratories tends to be early-stage research, meaning it is usually not directly connected to the development of a product. Patenting discoveries at a later stage, closer to the time of product development, makes more sense because there is more to protect. That's because basic information can be shared with others up until the point where patenting occurs so others can utilize that information to develop other medications or treatments.

In the end, there are few examples of patents that have made universities rich. Still, when universities want to defend the use of patents to protect discoveries made in their laboratories, they almost always cite the two most famous exceptions: Pablum and Gatorade.

SCIENCE MATTERS

A patent is a license issued by the government that gives an inventor the exclusive right, for a specific time period, to use or sell an invention. Patents were designed to prevent other inventors from stealing one person's idea and also as a way for the inventor to earn money.

PABLUM AND GATORADE GET ALL THE ATTENTION

Pablum, a cereal you may have eaten when you were a baby, is a Canadian invention developed in 1930 by three pediatricians at Toronto's Hospital for Sick Children, part of the University of Toronto. Alan Brown, Theodore Drake and Frederick Tisdall wanted to reduce ***infant mortality***, which is the death of children aged one or younger. The doctors' plan was to invent a healthy cereal that could be prepared quickly. Their invention contains vitamin D, which prevents ***rickets***, a disease affecting the development of children's bones. Tisdall

Few people know that Pablum, a cereal for babies, was a Canadian invention.

DADEROT/WIKIMEDIA COMMONS/ PUBLIC DOMAIN

SAFETY OVER PROFIT

It is estimated that the modern three-point lap-and-shoulder seat belt has saved millions of lives. This seat-belt design was invented in 1959 by Swedish engineer Nils Bohlin. At the time, Bohlin worked for the Volvo automobile company. Volvo's CEO back then was Gunnar Engellau, another engineer. He had a personal reason for wanting Volvo to come up with a better seat belt than the old-fashioned one that fastened around a person's waist. One of Engellau's relatives had died in a car accident, and a better seat belt would have prevented the death. Bohlin and his team studied reports on car accidents and tested their design until they got it right. The resulting three-point lap-and-shoulder seat belt wasn't only safer, it was also more comfortable, an important feature if you want people to wear seat belts.

Volvo could have made a windfall by patenting and licensing Bohlin's seat belt. But the company made Bohlin's patent immediately available to car manufacturers around the world. Volvo put safety before profit.

ANCHIY/GETTY IMAGES

sold the rights to manufacture the product to the Mead Johnson company in Chicago. For a period of 25 years, the Hospital for Sick Children received a ***royalty*** on every box of Pablum sold.

The sports drink Gatorade is the other famous example of a discovery that made a university rich—in this case, the University of Florida. In 1965 medical researchers at the university were asked by the school's football team—the Gators—to invent a drink to help prevent heat exhaustion. The researchers came up with Gatorade, an invention they patented in 1967. Gatorade became the world's most popular sports drink and has earned the University of Florida about $300 million in royalties!

An X-ray of a child with rickets.

SCIENCE PHOTO LIBRARY - ZEPHYR/ GETTY IMAGE

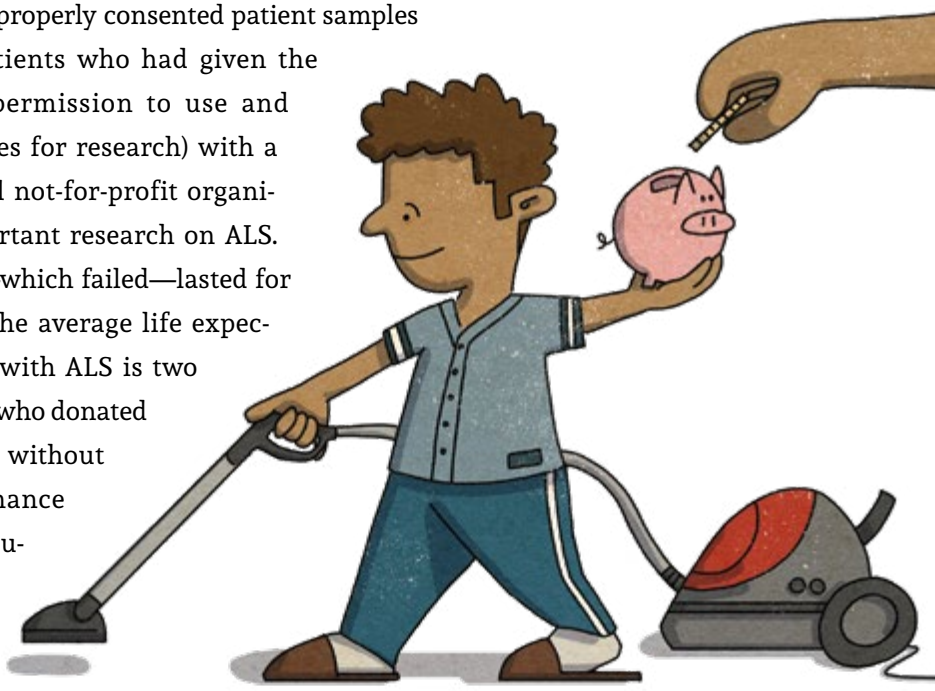
LET'S TALK CONTRACTS

Now that you understand how patents work, it's time to talk about contracts. A ***contract*** is a legal agreement usually having to do with the exchange of goods, services or money.

Remember how at the start of this chapter, I wondered whether you get an allowance? Getting an allowance is like having a contract—especially if you have to do something or several things before you get paid. Do you have to make your bed or take out the garbage in exchange for getting your allowance? Though you may never have signed an official document, if you have been exchanging services (such as doing a chore) in exchange for your allowance, well then, you are part of what can be called a contractual arrangement.

When it comes time to share scientific discoveries, it can take a lot of time (and cost a lot of money in legal fees) to figure out contracts. Lawyers often go back and forth before agreeing on a deal. Sometimes deals fall through, and no sharing takes place at all.

Recently, because of complicated contract issues, researchers at a Canadian university were unable to share a small number of properly consented patient samples (samples from patients who had given the university their permission to use and share those samples for research) with a large international not-for-profit organization doing important research on ALS. The negotiations—which failed—lasted for two years. Sadly, the average life expectancy of a person with ALS is two years. The patients who donated their samples died without having had the chance to contribute to valuable research on their disease.



SCIENCE MATTERS

Genes are individual pieces of our DNA. Our genes act like an instruction manual. They determine which traits—for example, height and eye color—we will inherit from our parents. Each of us has about 20,500 genes.

Geneticists work with powerful microscopes in order to see the effects of DNA mutations on cells.

SOLSKIN/GETTY IMAGES

PATENTING OUR PARTS

Patenting medical treatments is one thing, but in the 1980s universities and companies began patenting ***genes***. Don't our genes belong to us?

This practice of patenting genes led to what has been called the "genetic gold rush." These institutions and companies hoped to make a lot of money from their descriptions of the sequences of certain genes.

The most famous example of this practice is a Salt Lake City medical company called Myriad Genetics, Inc. Medical researchers at Myriad identified what are called the ***BRCA genes***—genes that, when they mutate, have been proven to cause most cases of inherited breast and ovarian cancers. Myriad used this information to develop a diagnostic test that let women know whether they carried the BRCA1 and BRCA2 gene mutations.

Because Myriad held the patent on these genes, other companies, university labs and hospitals could not create similar diagnostic tests. And because Myriad owned the

genes, the company could charge whatever amount they wanted for the tests.

ONLY FOR THE RICH

In 2013, after taking a diagnostic test developed by Myriad and learning she had the mutation, actor Angelina Jolie decided to have a preventive double mastectomy, a surgery to remove both of her breasts. The test is believed to have cost Jolie between $3,000 and $4,000. Many women at high risk of developing breast or ovarian cancer—meaning they had relatives with the diseases—could never afford the Myriad tests.

Things were different in Canada, where, thanks to Medicare, the country's publicly funded health system, women at risk of developing inherited forms of these cancers did not have to pay out of pocket for Myriad's diagnostic test.

FIGHTING BACK

When people realized what companies like Myriad were up to, they fought back. In 2013 the Association for Molecular

People from across the United States traveled to Washington, DC, to protest against Myriad, which had patented genes.

COURTESY OF BREAST CANCER ACTION

Pathology went to the US Supreme Court to argue its case against Myriad. At a protest in Washington, DC, before the case was heard, protesters carried signs, one of which read *Myriad Genetics Your Corporate Greed Is Killing My Friends.*

Harold Varmus, the co-founder of the Public Library of Science (you met him in chapter 1) was one of many scientists who objected to what companies like Myriad were doing. At a press conference, Varmus said, "It's in the interest of virtually everyone to keep ideas and basic discoveries about the laws and products of nature in the public domain."

The court ruled that isolated genes found in nature could not be patented. Today, thanks to that ruling, a diagnostic test in the United States similar to the one Jolie had costs a lot less money—about $250.

SCIENCE MATTERS

By the age of 70, a woman with a mutation on the BRCA1 gene has a 70 percent chance of developing breast cancer and a 39 percent chance of developing ovarian cancer.

BAD FOR OUR HEALTH

In chapter 1 we saw how the science world has focused too much on an individual scientist's publications (especially in prestigious journals). As we have seen in this chapter, when scientists, businesses and universities focus too much on making money, it too hampers the discovery process as well as the delivery of healthcare. That's bad for people's health.

Don't despair! Open science is working hard to fix these problems.

MANYBABIES CONSORTIUM

BABIES CONTRIBUTE TO SCIENCE

So far 2,000 babies from around the world have taken part in studies organized by the ManyBabies Consortium, a project that looks at best practices in developmental psychology research. Because this group adheres to open-science principles, it focuses on collaboration, not competition. One of the ManyBabies studies looked at whether children prefer infant-directed speech (a fancy way of saying baby talk) to more adult-directed speech. Sixty-nine labs from around the world participated in this study. The results showed that children do prefer baby talk, which is generally higher-pitched and uses shorter sentences than adult-directed speech. Another one of the ManyBabies studies is looking at whether infants prefer what they know over what is new.

THREE

BIG DATA

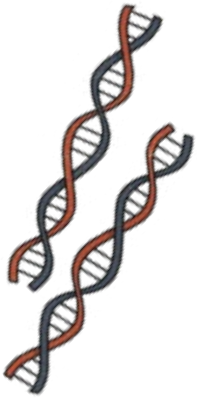
COMPUTERS AND THE INTERNET ADVANCE SCIENCE

As we have seen, the huge number of journals and the effects of big business changed the world of science. But those changes are tiny compared to the changes brought about by advances in technology.

Technology—in particular the widespread use of computers and the existence of the World Wide Web—has led to an information explosion as well as the ability to openly, rapidly and freely share information. All this is one more reason why we need open science. Thanks to technology, so much data is now available that it usually takes giant teams of scientists working separately and together to analyze this data and use

State-of-the-art computers such as the ones in this network server room are changing the world of science.

JASMIN MERDAN/GETTY IMAGES



their findings to do such things as develop new treatments for diseases.

Parents and teachers often warn kids about the downside of computers and the internet. They worry that if you spend too much time online, you'll get out of shape or won't get enough practice interacting with real people. They worry that you could become the victims of online bullying or that you will be exposed to fake news, which spreads easily online.

But of course the internet has also brought important, positive changes to humankind—and the world of science.

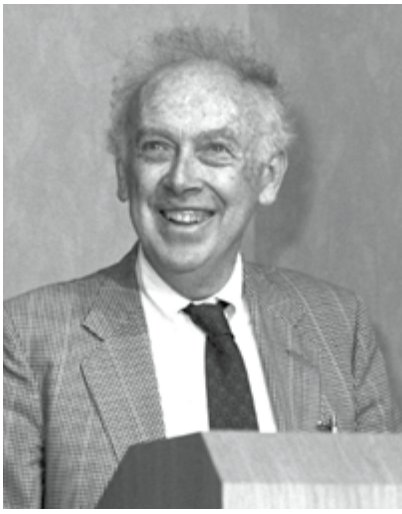
THIRTEEN YEARS TO SEQUENCE ONE GENOME

Here's an example. The goal of the Human Genome Project, an international science research project that began in 1990, was to identify the base pairs that make up human DNA by sequencing one ***genome***, which is all the DNA of one human

Today scientists have access to huge data sets in order to study DNA.
SOLSTOCK/GETTY IMAGES

cell. It took 13 years and cost US$2.7 billion to do this. Fast-forward to today when, thanks to technological advances, one genome can be sequenced in a day for about $800!

Here's another way to look at it. Twenty years ago a scientist could generate 10 points of sequence in a day. Today it is possible for one scientist working alone to produce a billion times that.



Molecular biologist and geneticist James Watson played an important role in the discovery of DNA and shared a Nobel Prize in Physiology or Medicine for discovering the structure of DNA.

NATIONAL CANCER INSTITUTE/WIKIMEDIA COMMONS/PUBLIC DOMAIN

WHAT TO DO WITH ALL THAT DATA? SHARE IT!

But what do we do with so much information? It's way too much for one scientist or even a team of scientists to handle. To achieve the best possible results, we need to openly share information. The information explosion doesn't affect only the world of medical science. The same is true for areas like astrophysics as well as nuclear and particle physics.

Eileen Meyer, an astronomer at the University of Maryland, works with data collected by the Hubble Space Telescope and the Chandra X-ray Observatory. Meyer studies the ***plasma jets*** sometimes produced by black holes. Plasma jets are so huge they can extend far out of the galaxies from which they originated. Meyer grew up in Kansas, where she and her parents often went out to the wheat fields to stargaze. She saved up to buy her first telescope when she was 12.

"Even 10 or 20 years ago, astronomy was kind of a closed world. People from less privileged countries, from smaller universities, and people who didn't have their own telescopes couldn't make discoveries," said Meyer. She's glad that has changed. Meyer has also observed that there are more tools and training to help people learn how to use the data collected by observational facilities.

Observational astronomer Eileen Meyer wants to understand how galaxies are formed.

COURTESY OF EILEEN MEYER

SCIENCE MATTERS

A black hole has so much mass and such strong gravitational pull that it pulls in light particles. That's why black holes cannot be observed directly. Instead astronomers study black holes by looking at the effects of their gravitational fields.

SEEING STARS

Early astronomers like Galileo Galilei worked alone or in small groups. They relied on telescopes to make their discoveries. But the field of astronomy now looks totally different than it did in Galileo's time. Those differences have a lot to do with big data.

Giant observation facilities—some of them spaceborne, like the Hubble Space Telescope, launched in 1990; the Chandra X-ray Observatory, launched in 1999; and the James Webb Space Telescope, launched in 2021—are producing a giant volume of data that is being analyzed by scientists in many countries. Thanks to the latest technology, this data is transmitted at speeds Galileo could never have dreamed of.

Best of all, most of this data is publicly available, so anyone who wants to reanalyze data sets can do so. That's how astronomers using archival data—images collected 20 years earlier by the Chandra X-ray Observatory—made the exciting discovery that thousands of black holes likely exist near the center of our galaxy.

CYCLOTRON

Particle physicists produce and work with something called ***cyclotron*** data.

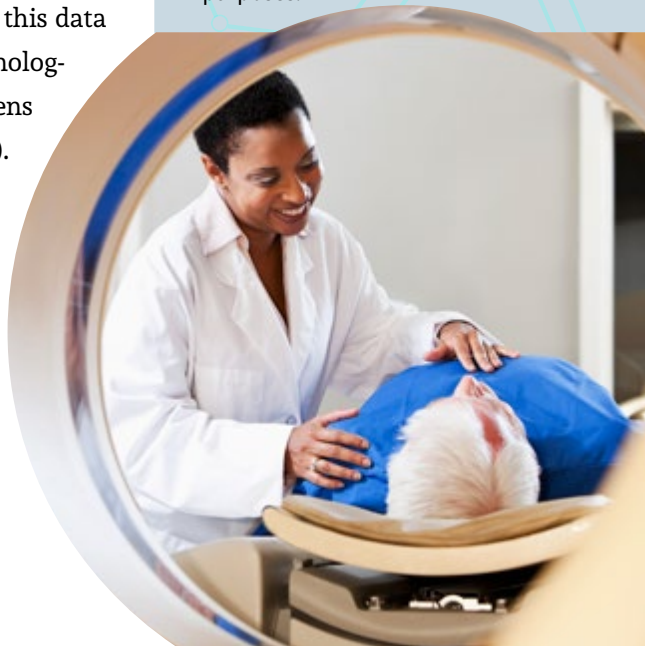
The cyclotron at the Montreal Neurological Institute-Hospital produces radioactive isotopes that are attached to probes. These probes are used in patients to highlight parts of the brain—for example, neurons that produce dopamine, the loss of which causes Parkinson's disease.

PET scanners, important for detecting and diagnosing diseases such as cancer, Alzheimer's and Parkinson's, use human-made radioactive isotopes.

MEDICAL DATA STANDS TO BENEFIT

The amount of data that can now be generated is nearly beyond our understanding. "In the last 20 to 30 years, we've moved into a new realm. We've got a tsunami of data," said Alan Evans, founder and scientific director of the Canadian Open Neuroscience Platform. Figuring out how to manage and use all this data is a huge challenge. In the world of medical research, this data includes genetic information, imaging, psychological tests, clinical assessments and biospecimens (materials such as tissue, blood and urine). "We have to develop all new strategies for analyzing data," said Evans.

Though the internet allows scientists to share and analyze data, the reality is that the giant amount of data Evans is talking about is seldom shared. That's because of many people's desire to keep things secret and control information.



This patient is about to have a PET scan, an imaging test doctors use to check for diseases.

KALI9/GETTY IMAGES

SCIENCE MATTERS

A cyclotron is a particle accelerator invented in 1930 by Ernest O. Lawrence at the University of California, Berkeley. The cyclotron accelerates particles by whirling them in a circle. The beam of charged particles produced by a cyclotron can be used in research and for medical or industrial purposes.

Alan Evans is an international expert on brain mapping.

COURTESY OF ALAN EVANS

Biobanks collect information and biological samples, such as this blood that has been separated into its different components.

NICOLA TREE/GETTY IMAGES

Usually the researchers producing all this data are only looking to test a single hypothesis. Take, for example, neuroscientist Guy Rouleau, director of the Montreal Neurological Institute-Hospital (often referred to as the Neuro), who studies, among other things, the genetic basis of a neurological disorder called ***restless legs syndrome (RLS)***. People with RLS have an uncontrollable urge to move their legs. The condition can make it hard to carry out simple tasks, concentrate and sleep. Rouleau and his team sequenced the genomes of 1,000 people with RLS. They were looking only for the genetic basis of that one disorder. But they realized their data could be used by other scientists studying entirely different illnesses, such as periodic limb movements disorder, as well as insomnia.

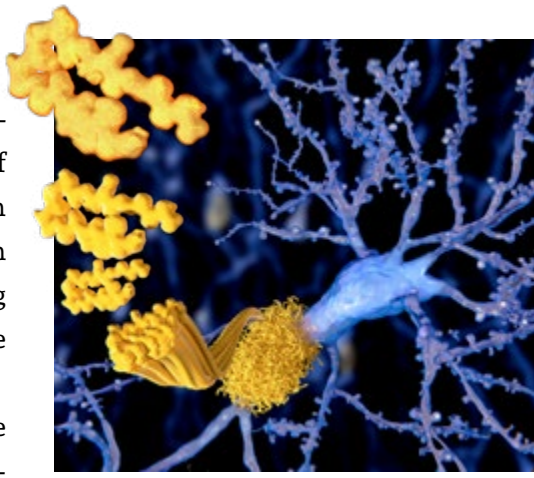
PUT IT IN THE BANK

"The system of not sharing data needs to change," said Rouleau. That's why in June 2021, the Neuro launched a facility and portal designed to share its massive amounts of data. It's an open-science ***biobank***—a collection of biological samples, clinical information, imaging and genetic data from patients with neurological diseases as well as healthy control subjects.

Alan Evans and his team are trying to understand the root causes of Alzheimer's. We know that in the brains of Alzheimer's patients there is a buildup of a toxic misfolded protein called ***amyloid***. This protein gets twisted together like tangled cables, choking brain cells. Medical researchers have been trying to invent drugs to reduce this buildup of amyloids. But because Evans's team was able to analyze huge data sets open to the scientific community, they

determined that Alzheimer's has a different cause—the under-clearance of amyloids, not the buildup of amyloids. Think of it this way: the brain has its own waste-removal system, which does not work well in Alzheimer's patients. Evans and his team are looking for ways to improve that system in the brains of people with Alzheimer's.

Open science allowed Evans and his team to make that discovery. Sharing data openly creates new opportunities for wide research. "If we have 100 scientists looking at data, and not just one, it's got to be better for science," Evans said.



Misfolded proteins called amyloid plaques are associated with Alzheimer's disease.

JUAN GAERTNER/SCIENCE PHOTO LIBRARY/ GETTY IMAGES

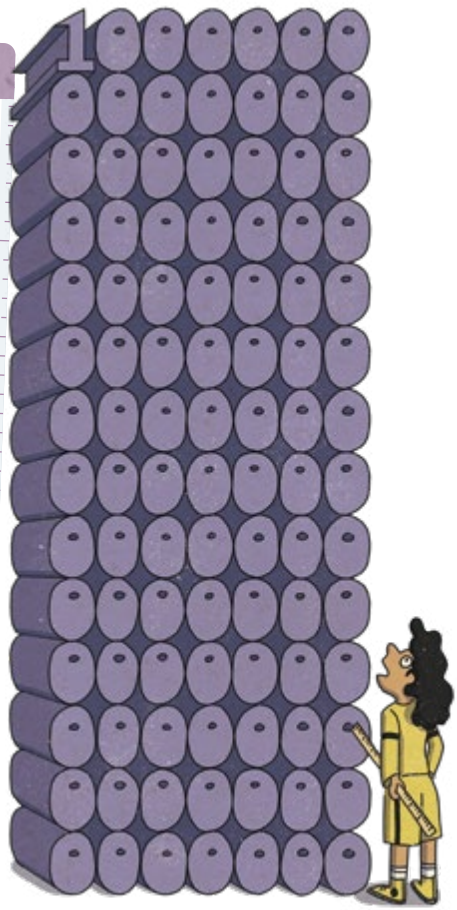
HOW BIG IS BIG?

Data sets have become too big for most ordinary computers to handle. Most of us can imagine a million—though if we counted out loud to one million at the rate of one number per second, it would take us 11 days and nearly 14 hours to count that far (and that's without taking breaks to eat, sleep or use the bathroom!).

We've all heard of millions, billions, trillions…but how big is big?

A million is one thousand thousands. A billion is one thousand millions. A trillion is one thousand billions. A quadrillion is a thousand million millions—or a million billions. How about a zillion? That's a trick question, since a zillion isn't an actual number. We use the word *zillion* to talk about a huge but nonspecific amount.

A byte is a unit of digital information. Megabyte refers to a unit of information equal to about one million bytes. Next comes the gigabyte. *Giga* comes from the Greek word for "giant." A gigabyte is a unit of information equal to one billion bytes. Then there's something called a terabyte, which is about a trillion bytes. A petabyte is one million gigabytes—or a 1 with 15 zeros after it! According to *Scientific American*, 2.5 petabytes would be enough to hold three million hours of TV shows.



MICE HELP RESEARCHERS

Adrien Peyrache is another neuroscientist based at the Neuro who openly shares the data he and his team collect. Peyrache has been trying to understand how our brains figure out where we are and how to get where we want to go next—kind of like the brain's internal GPS (global positioning system). The loss of this ***cognitive*** or intellectual ability can be an early sign of Alzheimer's.

Peyrache, who grew up in France, is a computer wiz. He's been coding since he was 12. He planned to work with artificial intelligence and robots until he discovered neuroscience.

Because neuroscientists like Peyrache can't peer inside a live human brain, they study the brains of live mice. In his laboratory, he and his team study the brain activity of mice as they freely explore an environment. This is Peyrache's way to understand the internal GPS of the brain.

Peyrache's background in coding comes in handy because he and his team produce an enormous amount of data. "In one simple four-hour experiment, we get 300 gigabytes of data."

SCIENCE MATTERS

Both mice and humans have what are called ***evolutionarily conserved brains***, meaning they have similar kinds of brain cells. Neuroscientists can implant an electronic recording device in a mouse's head, allowing neuroscientists to listen to neurons. They can also use a technique called ***optogenetics***, which uses light to turn on brain cells and activate certain neural circuits common to both mice and humans. These techniques help scientists gain a better understanding of the human brain.

Peyrache has a great comparison to help explain how big that is. "It's about the equivalent of 300 movies," Peyrache said.

Peyrache's ***raw data***, meaning data collected before it is processed or analyzed, is so huge it would take giant computers to store it all. So he and his team process the data, then share it online using open-access websites. "We make the extra effort," said Peyrache.

Why?

"There's no point in doing experiments that have already been done," Peyrache explained. Doing an experiment that has already been done and verified wastes time and requires more animal subjects. "The lives of animals are too precious for that," said Peyrache. He also gets professional satisfaction from sharing data. "When I release the data, I demonstrate I've done a good job. I make it possible for everyone to go back to my original data and see there was no cheating." Peyrache also likes knowing that some of his data is being used in colleges and universities around the world.

SCIENCE MATTERS

Most medical discoveries are based on animal research. That's because scientists rely on animals—typically rodents—to understand the causes of disease and come up with treatments for it. Mice share more than 98 percent of their DNA with humans and contract diseases such as diabetes, heart disease and cancer. Since mice don't live as long as we do, they can be studied for their entire lives. Animal subjects are cared for according to regulatory guidelines.

YOUNG SCIENTISTS EMBRACE OPEN SCIENCE

Peyrache was 38 at the time of this writing—pretty young to be an accomplished scientist. Most younger scientists believe in open science—maybe because, like Peyrache, they grew up around computers.

"I've noticed the younger generation are very into sharing," said Lynne Krohn, a McGill University neurogeneticist who was 32 at the time of our interview. Krohn is studying the genetics of rapid eye movement (REM) sleep behavior disorder, an early symptom of several diseases, including Parkinson's. Neurogeneticists like Krohn need large sample sizes for their research. She routinely works with samples and data from

Neurogeneticist Lynne Krohn shares her research into Parkinson's disease with scientists around the world.

CREDIT TK

SEEING BIGGER

The biobank at the Montreal Neurological Institute-Hospital is called C-BIGR. That's an acronym for Clinical, Biological, Imaging and Genetic Data Repository. But it is also meant as a reminder that scientists need to "see bigger"—beyond their own projects. Thanks to C-BIGR, all data generated in The Neuro's labs is openly shared with research teams around the world. The only condition is that researchers who want to use C-BIGR must submit valid scientific proposals and show they are following open-science principles. They must also demonstrate they have ***ethics*** approval from the universities with which they are affiliated.

To openly share big data we need not only scientists but also ***informatics experts***, computer specialists. In his lab at McGill University, Alan Evans works as closely with techies as he does with scientists. The software developers with whom Evans works could earn more money in the world of business, but they choose instead to contribute to scientific and medical research.

5,000 patients and ***controls***. "That's a lot of DNA from a lot of different people," she said. By working together and sharing biomaterials and data, laboratories help advance the field.

In 2019, together with Sara Bandres-Ciga, a postdoctoral student at the National Institutes of Health (NIH), Krohn founded the International Parkinson Disease Genomics Consortium Trainee Network (IPDGCTN). Their goal was to create a place for young neurogeneticists working on Parkinson's to work together and practice open science. IPDGCTN has 80 members from every continent except Antarctica. Every two months the group meets on Zoom to discuss research and new projects. Members even publish papers together. When they do, they always mention the trainee network. In the spirit of open science, they want to share information—as well as credit for their discoveries.

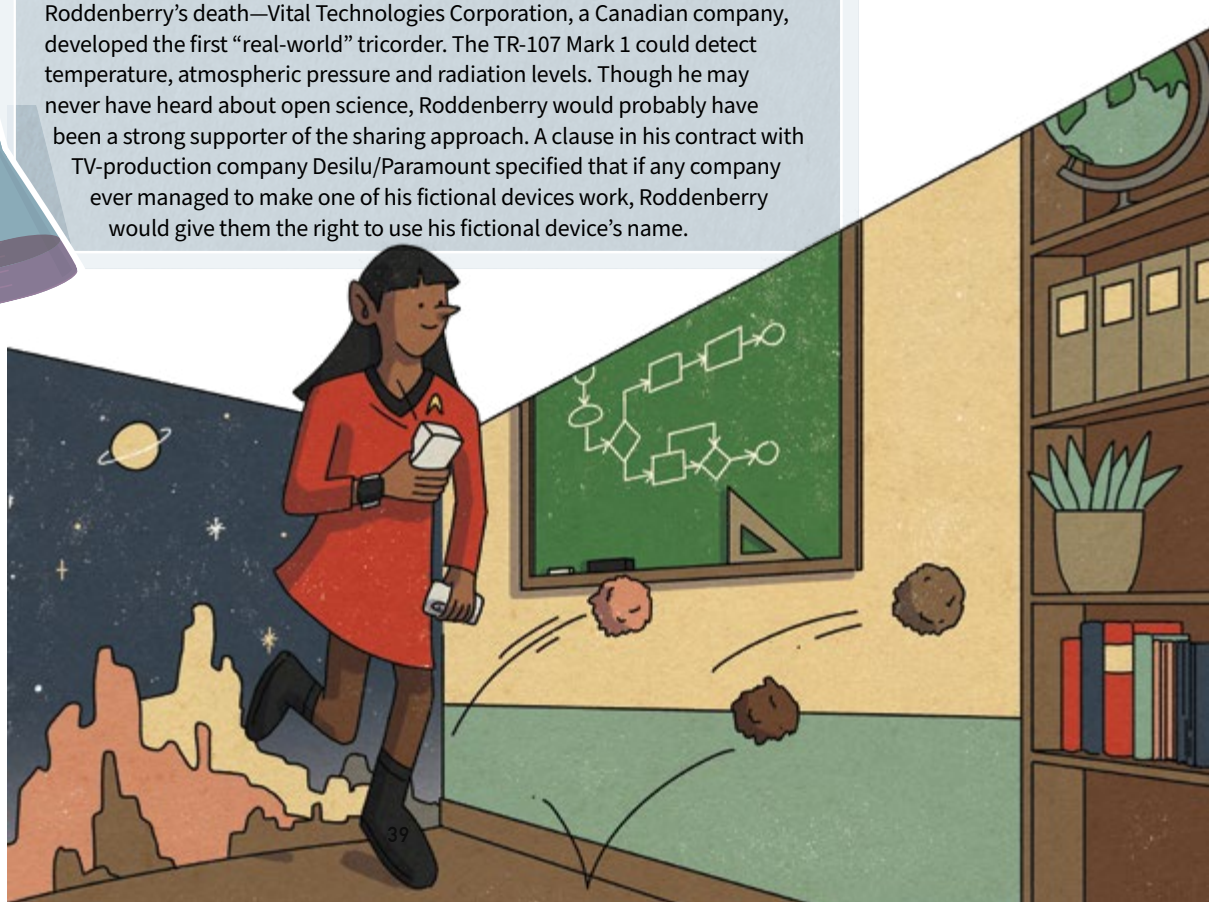
Krohn believes scientists should focus less on personal career success and more on helping to make the world a better place. "I think it's wonderful to accomplish a lot in your life and get your name on a big scientific paper. But it's even more wonderful to contribute to bettering patients' lives or advancing treatments or coming up with a cure," she said.

Krohn has a seven-month-old son named Liam. She hopes that by the time Liam grows up, open science will be the usual way things are done. "I want the whole world to be more collaborative," Krohn said.

EVER SEE THE TRICORDER IN *STAR TREK*?

If you've seen the old *Star Trek* shows or the more recent movies, you may have heard of the tricorder. In the TV series, the tricorder was a handheld device that had three functions: it could sense, scanning the environment and making detailed examinations; record data; and analyze data, or compute. In a 1966 memo, the show's creator, Gene Roddenberry, shared his idea for the device, which he described as "some sort of neat, over-the-shoulder recorder-electronic camera…which…can…make electronic photos of things, places etc."

Interestingly, some of Roddenberry's sci-fi product ideas influenced future electronic devices, including the cell phone! In 1996—five years after Roddenberry's death—Vital Technologies Corporation, a Canadian company, developed the first "real-world" tricorder. The TR-107 Mark 1 could detect temperature, atmospheric pressure and radiation levels. Though he may never have heard about open science, Roddenberry would probably have been a strong supporter of the sharing approach. A clause in his contract with TV-production company Desilu/Paramount specified that if any company ever managed to make one of his fictional devices work, Roddenberry would give them the right to use his fictional device's name.



FOUR

WE CAN ALL DO OPEN SCIENCE

SCIENTISTS SOMETIMES FOLLOW THEIR HEARTS

Most people think scientists are rational and detached. But like all of us, scientists have feelings. Sometimes the roots of scientific discovery are deeply personal and emotional. Some medical researchers devote their lives to the study of illnesses that have affected people they love. These researchers are not after big prizes, big profits or publication in prestigious journals. They just want the best possible treatments as soon as possible for those they care about—and for others suffering from the same diseases. They practice open science.

Like many scientists, Julian Symons has deeply personal reasons for doing the research he does.

CREDIT TK

SCIENTISTS DO RESEARCH FOR LOVED ONES

For many years scientist Julian Symons has been searching for a cure for respiratory syncytial virus (RSV). Symons, vice president at Aligos Therapeutics, has personal reasons for wanting to find a cure for RSV. His father, who died in 2004, suffered

Randy Schekman shared the 2013 Nobel Prize for Physiology or Medicine with James Rothman and Thomas C. Südhof.

BENGT OBERGER/WIKIMEDIA COMMONS/ CC BY-SA 4.0

from RSV. RSV infections are common in adults and usually not serious. But in people over the age of 65, and especially those with lung or heart problems, RSV can be fatal. A long-time smoker, Symons's father suffered from chronic obstructive pulmonary disease (COPD), which affected his breathing and made him vulnerable to the complications associated with RSV.

Nobel prize–winning biologist Randy Schekman (you met him in chapter 1) also has personal reasons behind his research. Schekman studies Parkinson's disease. His wife, Nancy Wells, was diagnosed with Parkinson's at age 48. She battled the disease for more than 20 years until her death in 2017.

PATIENTS AND THEIR FAMILIES GET IN ON THE ACT

It's not only trained scientists like Symons and Schekman whose research is motivated by the desire to help their loved ones. Patients themselves want to contribute to research and discovery. So do their families. Thanks to the rapid sharing of information made possible by the internet, anyone can contribute to research and discovery. Some patients have even invented treatments. This phenomenon has become so common and important it has a name: user innovation. The term comes from the business world.

User innovators come up with solutions to improve their lives. It is up to them to decide if and how they will share their discoveries. They may choose to share their findings with other users or with people who may be able to create a product, or perhaps start a business to sell a product they have created.

If science is open and everyone has access to scientific research and data, we can all contribute to scientific research and even become user innovators ourselves. By doing so, ordinary citizens—and this includes kids!—can help speed up discovery.

SCIENCE MATTERS

The main treatment for Parkinson's is levodopa. This drug, approved in 1970 by the US Food and Drug Administration (FDA), the agency responsible for protecting public health, was discovered by Oleh Hornykiewicz, a pharmacologist at the University of Toronto and the Brain Research Institute in Vienna. Levodopa helps the brain replenish its supply of dopamine, a neurotransmitter important for normal movement.

LESSONS FROM USER INNOVATION

Eric von Hippel, a professor at the Massachusetts Institute of Technology (MIT) Sloan School of Management, studies user innovation. For von Hippel, user innovation starts with the desire to solve a problem. "User innovation is when you create something to use it," said von Hippel. Anytime someone runs into a problem for which there is no solution, there is an opportunity for user innovation. "Users understand their needs better than producers," said von Hippel.

Von Hippel was 12 when he started thinking about user innovation. At the time, his father taught ***materials science*** at MIT, and on Saturdays he brought his son with him to work. Young von Hippel observed the work going on in the labs. "I discovered that scientists were inventing things they needed—for example, a laboratory research tool to analyze a crystal. They figured out an instrument to do it with because they knew what they wanted," von Hippel told me.

In his teens, von Hippel himself became an inventor. He and his family were living in New Hampshire, and his parents wanted him to cut wood for the woodshed. But the wood was so heavy it was difficult to move. Von Hippel devised a solution. "I made my invention out of a chainsaw and a lever," he said.

THE REWARDS: FUN AND LEARNING

Von Hippel is against patents. He believes most user innovators are not looking to get rich from their inventions. "When they innovate for themselves, they benefit from the fun of it—and the learning," he said. "Their profit is self-reward. Shifting to user innovation makes it possible to have things more open."

SCIENCE MATTERS

User innovation refers to innovations or inventions that come directly from consumers (or users) rather than from industry.

MEET LUCIE MUMLEY, ASPIRING SCIENTIST

"One of the things I'd like to be when I grow up is a scientist. I'd like to discover new things and know more about animals and nature," said 11-year-old Lucie Mumley, a fifth grader at École Notre-Dame-de-Grâce in Montreal. One weekend in spring 2022, Mumley's mom, Janet Lewis, heard about family-friendly outdoor events at Montreal's Falaise Saint-Jacques, an escarpment located close to a major highway. Lewis brought Mumley and two of her friends to the escarpment, where they hiked around a ravine and spotted a hole dug by an animal. "It was potentially a fox hole," said Mumley. Next year Mumley says she'll photograph her observations and share them online. "I would like to take part in the City Nature Challenge. I like sharing. I try to do the most sharing possible," said Mumley.

User innovation plays an important role in the world of medicine. It is estimated that more than half of new treatments and devices for patients suffering from chronic diseases such as cystic fibrosis, asthma and diabetes were developed by patients or their friends and relatives.

IMPROVEMENTS TO THE COLOSTOMY BAG

After abdominal or colon surgery, some patients have to use a ***colostomy bag***—a bag that collects ***fecal matter*** (the scientific term for poop) from the digestive tract. Sometimes the bag is temporary, and after the patient has had time to recover, doctors perform a surgery so it is no longer needed.

The colostomy bag is believed to date back to the 18th century. You can imagine that back then, people with these bags probably didn't talk much about what they were going through. Maybe they felt embarrassed about not being able to go to the bathroom in the same way most of us do. But today, because the internet brings together so many people from so many places, it makes it easy to connect with others in similar situations.

Users of the colostomy bag have created their own online communities. Some have come up with modifications that have been used by industry. Michael Seres was 12 when he was diagnosed with ***Crohn's disease***—an illness that can cause abdominal pain, severe diarrhea and malnutrition. Seres had his first surgery at age 14. A long-time user

According to some estimates, nearly one million people in the United States use a colostomy bag.

LORENZO CAPUNATA/GETTY IMAGES

of a colostomy bag, Seres knew all the things that could go wrong. The bag could burst or leak. So Seres invented the SmartBag—a drainable colostomy bag with sensors that monitor for leakage, inflammation and possible infections. Seres, who died in 2020, believed patients needed to be part of the discussion around medical issues. His SmartBag, which got US FDA approval in 2014, has helped millions of people.

CREDIT TK

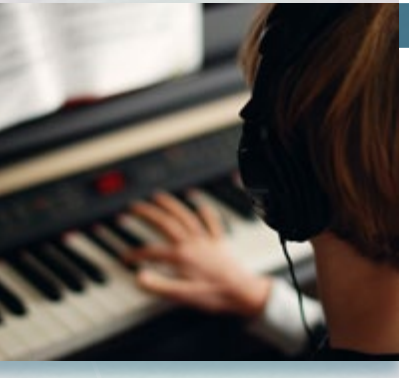
A DO-IT-YOURSELF ARTIFICIAL PANCREAS

Another example of patient innovation is the artificial pancreas. Frustrated by the slow pace of innovations for the management of diabetes, a disease that affects how the body turns food into energy, computer-savvy parents of children with diabetes got together and came up with this groundbreaking invention. Some of these parents launched the #WeAreNotWaiting movement and began to develop their own do-it-yourself artificial pancreas systems (DIYAPS) that used smartphone technology, continuous glucose monitoring and insulin pumps to run openly shared algorithms that led to better glycemic control (the medical term for typical levels of blood sugar in a person with diabetes)—and a better life for their kids.

CREDIT TK

ONLINE SOLUTIONS

Founded in 2014, patient-innovation.com is a nonprofit online platform where patients and caregivers around the world connect and post solutions to cope with diseases. In other words, the website is all about sharing. More than 750 solutions are posted on the website.



KRISTINA STRASUNSKE/GETTY IMAGES

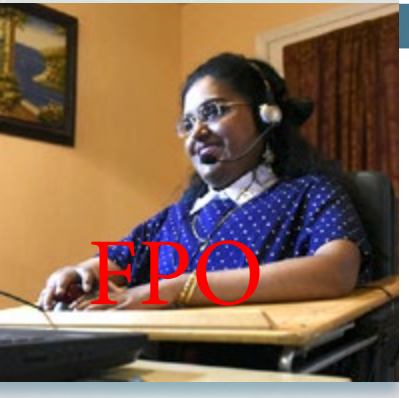
PLAYING PIANO CAN BE GOOD MEDICINE

Diogo Lopes, a young man with ***Charcot-Marie-Tooth disease***, an inherited disorder that causes nerve damage mostly in the arms and legs, discovered that playing piano helps maintain his hands' independence by improving their dexterity and increasing sensation in his fingers. Lopes posted that after playing piano for one hour, he takes 10 minutes to rest. His advice helps others with the disease who want to try taking up piano.

CREDIT TK

THIS FROG COMES TO THE RESCUE

Taylor Moreland's son Brody was born with ***spina bifida***, a birth defect that means a part of Brady's spine did not form normally. When Brody was unable to crawl, the Morelands bought their son a specialized wheelchair—which didn't work. So Taylor created a homemade device he called The Frog. The device allows Brody to crawl, play with his cousins and even chase the family cat. Since posting his device on patient-innovation.com, Taylor has produced The Frog for 20 other kids who have difficulty moving their legs.



CREDIT TK

ROBOT, MEET MATTRESS!

Kavita Krishnaswamy is another proud patient innovator. Krishnaswamy, who was born in India but moved to the United States as a child, has a rare genetic disorder called ***spinal muscular atrophy*** and is confined to a wheelchair. Krishnaswamy wanted to be more independent, so she invented a robotic mattress with air chambers that can be inflated or deflated by voice command in order to adjust height levels, resulting in pressure relief and a better rest. By using this device she does not have to rely on caretakers to adjust her mattress. She hopes to see more assistive robotic

devices to help people with disabilities as well as seniors who may be finding it harder to get around and accomplish tasks they once did easily. “I want to travel to more places, interact with more people and increase mobility for people with disabilities. To improve the quality of life, people should be as independent as possible and new technology can help accomplish that,” said Krishnaswamy.

LET'S DO SCIENCE

Even if we are not personally affected by a disease, even if we don’t wear a white lab coat, we can still contribute to science.

SURFER KIDS BECOME USER INNOVATORS

Skateboards, which first appeared in the 1950s, were invented by kids in California. These kids were surfers who wanted to bring surfing to the streets. They came up with a simple invention—they attached roller-skate wheels to wooden boards and voilà, the skateboard craze was born. These young inventors didn’t bother with patents. Instead they openly shared their invention. They figured the more skateboarders, the better! In fact, one of the philosophies of skateboard culture is that the pastime should be open to anyone, regardless of race, gender or social class. Today most skateboarders are under 18 years old. According to the Public Skatepark Development Guide, nearly 10 percent of American teens have ridden a skateboard in the last year. In 2022 skateboarding became an Olympic sport.

KEEP YOUR CELL PHONE CHARGED

In 2016 the cities of Los Angeles and San Francisco went head-to-head in the world's first City Nature Challenge (CNC)—a friendly competition in which citizens documented the wild plants and animals in their urban areas. By 2021 the competition had spread around the world—more than 50,000 people participated, registering more than a million observations of some 45,300 different species. In 2022, 400 cities from six continents joined the challenge. Participants use their cell phones or digital cameras to record and upload their observations during a four-day period in early spring. Technoparc Oiseaux, a local environmental group, co-hosts the event in Montreal. "We know scientists can't be everywhere at once, so this is a way for regular people to contribute to citizen science," said Katherine Collin of Technoparc Oiseaux. Collin stresses that the focus of the CNC is not competition. "It really is a collaborative exercise of trying to find the wildlife and wild plants...and to build those connections to nature," she said.

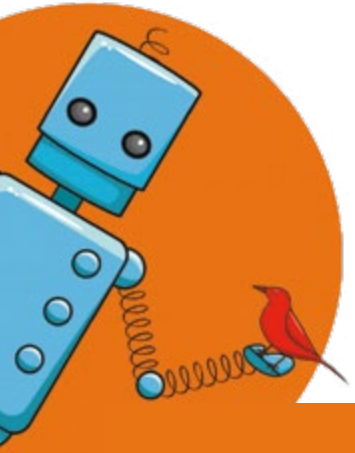
In addition to being an environmentalist, Katherine Collin teaches English at Vanier College in Montreal.

CREDIT TK

Citizen science is the term for public participation and collaboration in scientific research. Most citizen scientists are volunteers, meaning they are not paid for their work. And don't forget, kids are citizens too!

We have already seen how important it is to collect data. By contributing data, we can help speed up discovery. Some examples of citizen science include monitoring local water quality, submitting photographs of birds or butterflies you have seen or even analyzing spiral galaxies online.

SCISTARTER



EVEN SCIENCE NEEDS HELPING HANDS

SciStarter is an organization founded in 2011 by Darlene Cavalier. At the time, Cavalier, now a professor at Arizona State University, was doing her master's degree in liberal arts at the University of Pennsylvania. She was fascinated by the idea of how people who are not scientists can contribute to science. Another cool thing about Cavalier is that she had

been a cheerleader for the 76ers, a professional basketball team in Philadelphia. So Cavalier brought her cheerleading skills to science.

Cavalier created a website that would allow everyone to become a citizen scientist. SciStarter accounts are free. Kids aged 13 and older can have their own account. Those who are younger need to get a parent or teacher to set up an account and help them use it. Today SciStarter has 150,000 registered users.

Anyone who logs on to SciStarter can add their own project to the website. At last count, more than 3,000 projects, events and tools were registered. "Researchers don't have enough eyes and ears to do all the work we need done," said Caroline Nickerson, SciStarter's program manager. "Researchers need you to become a citizen scientist and collaborate with them to do meaningful scientific research. It also gives the public a way to be part of something bigger than themselves."

Darlene Cavalier, a professor at Arizona State University, believes citizen science can contribute to research.

BACHRACH PHOTOGRAPHY

QUIT STALLING!

Here's a cool example of a SciStarter project—*Stall Catchers*. *Stall Catchers* is a video game in which players catch "stalls"—which are actually clogged blood vessels—in movies of mouse brains. That's because scientists at Cornell University believe they have discovered links between clogged blood vessels and Alzheimer's. By reducing the number of clogged blood vessels in mice, scientists were able to restore memory in mice. But the scientists realized they would need to study a lot of

MORE THAN A CHOCOLATE FACTORY

You've probably heard of Roald Dahl, author of *Charlie and the Chocolate Factory*. But few people know Dahl was also a medical inventor. When Dahl's son, Theo, was four months old, he was hit by a New York City taxicab. As a result Theo developed hydrocephalus, a buildup of water inside the brain. Together with friend, engineer and toy inventor Stanley Wade and Kenneth Till, a neurosurgeon at London's Great Ormond Street Hospital, Dahl developed a neurosurgical shunt for children with hydrocephalus. The device, known as the Wade-Dahl-Till valve, helped drain excess water from the brain. It was used on nearly 3,000 children. Dahl and his co-inventors insisted the device be free for all patients. This story proves that people have always wanted to contribute freely and openly to help those they love, as well as others facing similar challenges.

This framed Wade-Dahl-Till valve once belonged to Roald Dahl and hangs inside the writing hut in Solo Gallery.

CREDIT TK

data—which would take years. So they turned to citizen scientists and SciStarter for help. Players score blood vessels as moving or stalled. By doing so, they may be helping to speed up Alzheimer's research.

MORE THAN MEMORIZING

Stall Catchers is proof we can all contribute to science—even if we do not think of ourselves as sciency. When she was a kid growing up in Orlando, Florida, science scared Nickerson. "I thought it was all memorization and tests," she recalled. But when Nickerson first learned about citizen science, in college, she got hooked. "Citizen science is about a way of discovering new information about the world," she said. "It's a way of thinking. You can do science at any age, no matter who you are or where you are."

Organizations like SciStarter are helping open up the world of science. "Kids can do science. No matter what job you end up doing, you can do science for the rest of your life!" said Nickerson.

Caroline Nickerson lives in Florida, where she works helping young innovators contribute to their communities.

EVA FLIS PHOTOGRAPHY

SCIENCE CHEERLEADERS

THREE CHEERS FOR SCIENCE!

Darlene Cavalier and Caroline Nickerson are both part of Science Cheerleaders, a sister organization of SciStarter. Science Cheerleaders' goal is to challenge stereotypes and encourage kids and young women to pursue careers in ***STEM*** (science, technology, engineering and math) fields. The stereotype associated with cheerleaders is they're pretty and like to dance and shout. So you may be surprised to learn that Science Cheerleaders has more than 300 members, including current and former National Football League, National Basketball Association and college cheerleaders who are working in STEM fields.

Nickerson competed in Miss Earth USA—an international beauty pageant that promotes environmental awareness. She was named Miss Louisiana Earth. "I wanted to raise awareness about environmental issues affecting Louisiana and across the Gulf Coast," she said. She also wanted to spread the word about citizen science.

Nickerson loves being an ambassador for citizen science. "Once you have a crown or sash, or your pom-pom, you can make science accessible to all. You can bring science to people, rather than keeping it in institutions," she said.

FIVE

MAKING ROOM FOR EVERYONE

WHITE MALE PRIVILEGE

Quick! Name the three most-famous scientists you've ever heard of. Did you come up with Albert Einstein? Stephen Hawking? Maybe Thomas Edison or Louis Pasteur?

With a few notable exceptions—like Marie Curie!—the best-known scientists have been white men who grew up in developed countries and had the privilege of going to school, having access to books and later attending some of the world's top universities.

If science is going to be open, it has to be open to everyone—no matter our gender, where we live or whether we can afford to attend university.

Here's another way to look at it—let's say you are playing cards, and the

SCIENCE MATTERS

Inequity starts early. Children who are malnourished, unable to attend school and have little or no access to books are less likely to succeed than those who are more privileged.

person dealing the cards finds a way to give you the best ones. If that happens, the game is rigged, making it impossible, or at least very difficult, for anyone else to win. That's not fair, is it?

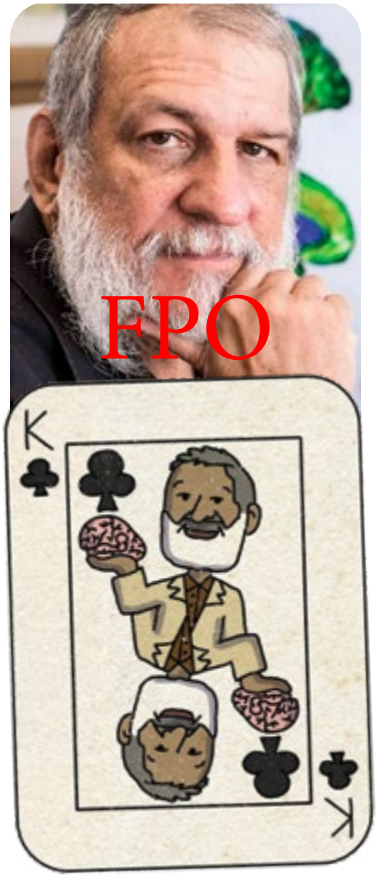
EQUITY, DIVERSITY AND INCLUSIVITY IN SCIENCE

The word ***equity*** means fairness. Like a card game, the world of science must be fair. The deck shouldn't be stacked so that only certain people are likely to succeed. The world of science also needs to be diverse and inclusive. The word ***diversity*** refers to differences. In humans, these differences may have to do with race, gender, disability status, nationality, religion, sexual orientation, age and socioeconomic background. ***Inclusivity*** means no one gets left out—and everyone feels included.

Here's another question for you. Shouldn't a young Black female from sub-Saharan Africa who dreams of becoming a scientist have the same opportunity as a young white man from a wealthy North American family? The truth is, it will be much harder for the young Black woman from sub-Saharan Africa to realize her dream.

In 1990 Pedro Valdés-Sosa co-founded the Cuban Neurosciences Center.

CREDIT TK



FEEDING YOUNG BRAINS

Malnutrition affects the development of children's brains. "Babies and young children who are malnourished will be disadvantaged for the rest of their lives," said Pedro Valdés-Sosa, a Cuban brain researcher who is a strong supporter of open science. Valdés-Sosa has been involved in a long-term study in Barbados, a country in the Caribbean, where, in the

1960s, doctors and scientists observed a high rate of malnutrition. Scientists monitored the brain health of these children as they grew up. "Kids who had been malnourished often developed attention deficit disorder (ADD). By the time they were in their 50s, their brains were aging prematurely," said Valdés-Sosa.

These Barbadian children attended the launch of the country's Protect Our Children campaign, which focused in part on healthy eating.

CREDIT TK

FEEDING YOUNG MINDS

For kids to succeed in any field—including science—they need to eat well. They also need access to education and resources such as books. Many librarians also support open science. After all, their mission is to make information—which can mean books as well as scientific data—available to everyone. Shouldn't a girl from Afghanistan have access to school and books so she can realize her dream of contributing to the world of science?

These young women are fortunate to have access to a library. Many people around the world do not have this privilege.

FSTOP123/GETTY IMAGES

Open science requires open access to books, scientific research and data. This also means internet access, something not always easily and cheaply available in developing countries or remote regions.

In many parts of the developed world, kids take school, libraries and internet access for granted. If they want a book, they can find it at the local library. If the library doesn't have it, there is a good chance the library can arrange an inter-library loan and borrow the book from another library.

THE POWER OF STORIES

But some kids grow up without books altogether. Bethzy Gianella Chiang was born and raised in Mollendo, a small village in southern Peru, where she lived until she was 17. Mollendo had no library or bookstore. "We only had school-books. We didn't read for fun. We only read what was mandatory for school," Gianella Chiang recalled. But when she was 15, a friend of her sister's lent Gianella Chiang a book by Colombian novelist Gabriel García Márquez—and Gianella Chiang discovered the power of stories.

Today Gianella Chiang lives in The Hague in the Netherlands, where she is the operations manager for Biblionef, a nonprofit organization that aims to give all children access to books. Biblionef collects and donates books to children living in countries where they lack easy access to books.

BRINGING BOOKS TO KIDS EVERYWHERE

The organization works to get books to schools in countries such as South Africa and Ghana. But as Gianella Chiang explained, getting books to kids is only the start. "We need

to nurture a reading culture," she said. Some of the villages Biblionef sends books to do not have computers. The organization also trains teachers in reading development and library management. For a recent project in northern Ghana, Biblionef created rolling bookshelves so books could be moved from one classroom to another. Biblionef has also established three community libraries in Ghana so books can be available not only to kids but to grown-ups too. While the organization recognizes that it is important for children to learn to read English, it also attempts to supply them with books in their own languages and stories about children who live in the same countries as them.

These children are reading books donated to their schools by Biblionef.

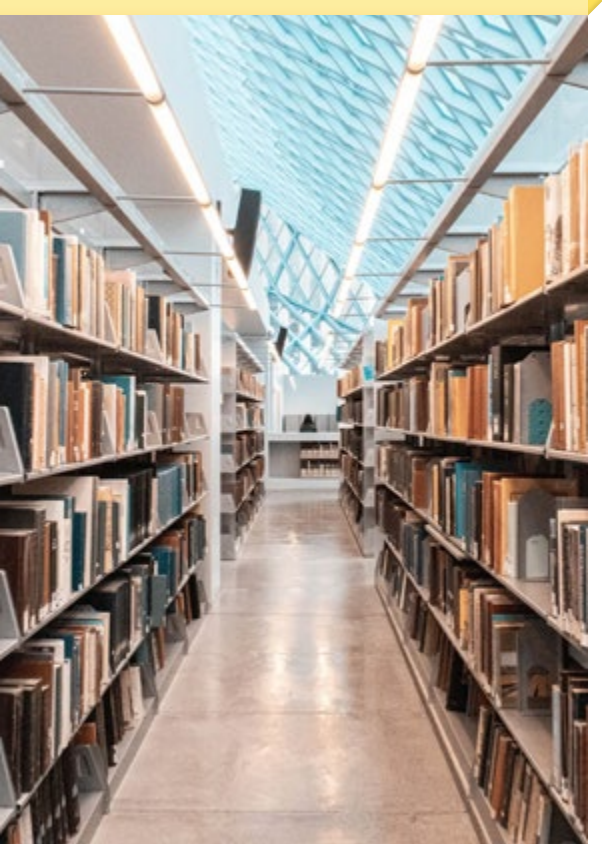
CREDIT TK

This girl is reading a story about one of the world's most inspiring people.

CREDIT TK

AFRICAN SCIENTISTS LACK OPEN ACCESS

In chapter 2 you learned about APCs—article processing charges. These are fees scientists pay for their work to be published in science journals. Universities and governments usually cover the cost of APCs. In Africa, however, this seldom happens. And because African scientists tend to be poorly paid, they cannot afford to pay APCs themselves. According to the journal *Nature*, the average monthly salary of a scientist in Ethiopia is US$365. In Uganda the cost of the APCs for two articles would cover a year's tuition and field expenses for a graduate student. You may remember that some journals, such as those published by the Public Library of Science, offer waivers to scientists from low-income countries. But most journals do not have a waiver system. To contribute to scientific research, African scientists must be able to be published in—and read—scientific journals.



BURST THAT BUBBLE

Gianella Chiang believes kids who have access to books at home and at school, and who can go to a neighborhood library, must realize how lucky they are. "They can do this," Gianella Chiang tells me, snapping her fingers, "and get any book where they can see themselves, in their own language, a nice, funny, lovely book."

Valdés-Sosa agrees that those of us living in developed countries must recognize how privileged we are. "Most people from higher-income countries live in a bubble. They need to become aware that it's important to learn how other people live," he said.

GROWN-UPS NEED OPEN ACCESS TOO

It's not only kids who need access to books—so do grown-ups. LIBER, the Association of European Research Libraries, has headquarters in the same building in The Hague as Biblionef. LIBER works to ensure that people in all countries have access to world-class science. The organization has 450 members in Europe, most of which are research libraries. Libraries and the people who use them tend to be far less privileged in some areas—for example, southern and eastern Europe—than

in countries such as the Netherlands or the United Kingdom. "A population served by a library in Serbia may not be well-educated, or there may be insufficient budget to hire educated staff," said Astrid Verheusen, LIBER's executive director.

But even with proper nutrition and access to books and research libraries, some individuals who hope to pursue careers in science face other obstacles.

RACISM IN THE WORLD OF SCIENCE

Black Lives Matter is a political and social movement protesting incidents of police brutality and racially motivated violence

NEXT GENERATION

"I believe every child deserves access to a quality school," says Mashea Ashton, who in 2018 founded Digital Pioneers Academy in Washington, DC. The academy, which does not charge tuition, has a computer-science focus. Ashton wanted to help develop the next generation of innovators. She also wanted to ensure that underprivileged youngsters in the Washington, DC, area would have the opportunity to study computer science and perhaps pursue careers in the field. Ashton says that at her school, faculty and students are "always eager to collaborate, innovate and learn together."

Mashea Ashton studied special education before going on to found Digital Pioneers Academy.

CREDIT TK

These young people are protesting the murder of George Floyd, who was killed by a police officer in 2020.

COLE BURSTON/GETTY IMAGES

NO, I MEAN A SCIENTIST

When Mae Jemison told her kindergarten teacher that she wanted to be a scientist, the teacher said, "Don't you mean a nurse?" Jemison, who went on to become the first Black woman to travel into space, recalls putting her hands on her hips and telling her teacher, "No, I mean a scientist." In 1992 Jemison served as mission specialist on the space shuttle *Endeavour*. In addition to being a medical doctor and engineer, Jemison trained as a dancer. These days, Jemison runs BioSentient Corporation, a medical devices company. She also founded The Earth We Share (TEWS), a nonprofit international science camp for kids aged 12 to 16. As Jemison says, "We share one planet Earth and must find and act on solutions to global problems."

When she was aboard the *Endeavour* in 1992, Mae Jemison ran bone cell research experiments.

WIKIMEDIA COMMONS/NASA/ PUBLIC DOMAIN

against Black people around the globe. International protests peaked following an incident on May 25, 2020. On that day George Floyd, a Black man suspected of having used a counterfeit bill, was arrested by Minneapolis police. A police officer pinned Floyd down and killed him by kneeling on his neck and back for over nine minutes. The murder, captured on a video that went viral, led to an international show of support for the Black Lives Matter movement.

That same day, another racist incident involving the mistreatment of an African American man took place and the video of it also went viral. This incident occurred in New York City's Central Park and involved a citizen scientist.

ETHICAL OPEN SCIENCE

Ethics is about differentiating right from wrong. Ethics affect how we live and make decisions. Here's an example. At the store, you find a pair of shorts you love. What if you discover the shorts were produced by child laborers forced to work for little or no money in what are known as sweatshops in countries like Bangladesh? Do you buy the shorts?

To behave ethically, you must be honest and fair, treat others with respect and do your share to make the world better. For open science to be ethical, it must respect confidentiality. People may want to ensure that personal and sensitive information about themselves or members of their families, such as their names and health records, is not shared. There can be repercussions if others have access to this type of information. An insurance company might refuse to provide coverage to someone with a strong family history of cancer. Clinical researchers must get what is called ***informed consent*** from the people who participate in their studies. Informed consent is about more than signing a form—it's about having the freedom to make a well-informed decision. It means participants in a drug trial, for example, must have agreed to participate voluntarily and been informed about all aspects of the trial that concern them, including possible health risks.

UNETHICAL SCIENCE

Scientific research has not always been ethical. One of the most disturbing examples is the Syphilis Study at Tuskegee Institute. In 1932, 600 Black men were recruited for a secret US Public Health Service medical study. Three hundred and ninety-nine of the men were diagnosed with syphilis, a sexually transmitted disease. The other 201 men were part of a control group. Researchers wanted to study what would happen if syphilis was not treated. The study extended for 40 years.

When in 1945 the US Centers for Disease Control announced that penicillin was an effective treatment for syphilis, the men in the study were not given penicillin. None were offered an opportunity to give their informed consent, nor were they ever informed they were not being treated for syphilis. Instead they were told they were being treated for "bad blood"—a term used at the time to describe several ailments, including anemia, fatigue and syphilis. In 1972 the *New York Times* ran a front-page story about the Tuskegee experiment. Two years later the US Congress passed the National Research Act, which aims to prevent the exploitation of human subjects by researchers. In 1997 US president Bill Clinton apologized to the eight remaining survivors of the Tuskegee study. In his speech, Clinton admitted, "The United States government did something that was wrong—deeply, profoundly, morally wrong."

WIKIMEDIA COMMONS/ NATIONAL ARCHIVES ATLANTA, GA (U.S. GOVERNMENT)/ PUBLIC DOMAIN

MEGAN VARNER / STRINGER

Christian Cooper got hooked on birdwatching when he was growing up on Long Island, NY, and his parents encouraged him to build a bird feeder in his woodshop class.

CREDIT TK

Christian Cooper was bird-watching when he ran into a white woman named Amy Cooper (the fact that they have the same last name is a coincidence), whose dog was off leash. When Christian Cooper told her that her dog needed to be leashed, Amy Cooper said, "I'm calling the cops...I'm gonna tell them there's an African American man threatening my life." Cooper captured the confrontation and Amy Cooper's threat on video.

This incident outraged many people, including members of the scientific community. They saw it as proof that the world of science has a lot of work still to do when it comes to equity, diversity and inclusion when a Black man can't safely be a citizen scientist in his own community.

WILDLIFE HEROES

In response to the Cooper incident, Black AF in STEM, a group of Black students and professionals in STEM fields,

came up with the idea of Black Birders Week, a weeklong series of events to highlight Black nature enthusiasts and help make Black scientists more visible. Above all, it reminds us that both the world of nature and the world of science must be open to all of us.

Black Birders Week has meant a lot to Tolga Aktas, a Black conservation biologist based in the United Kingdom. "Growing up, there weren't many outlets showing diversity, so I was only able to be inspired by white conservationists and naturalists," he said in an

CREDIT TK

Karidia Diallo is a South African doctor and scientist who does important research related to the treatment of HIV/AIDS.

CREDIT TK

interview for the TV show *Nature*. "The Black Birders Week movement allowed me to see that there are many Black wildlife heroes out there. It reassures me that everyone can make a difference towards our planet."

Aktas's words remind us that no matter our race, gender, disability status, nationality, religion, sexual orientation, age or socioeconomic background, we can all contribute to the world of science. By openly sharing scientific research so that it is more accessible to people everywhere, open science is helping transform the world of science, making it more equitable, diverse and inclusive.

If you know what sorts of birds are in your neighborhood, then you can research ways on how to keep them safe and protected.

RAWPIXEL/GETTY IMAGES

FPO

ALL OF US

According to the Pan American Health Organization (PAHO), 80 percent of research money benefits only 20 percent of the world's population. Nancy Kass, vice provost of Johns Hopkins University in Baltimore, is an expert on the ethics of science research. Kass is pleased that institutions such as National Institutes of Health (NIH) are insisting on something called "demographic variation" in research—meaning the agency will not fund projects that do not include participants of different genders, races and ethnicities.

Kass chairs the ethics review board for the All of Us Research Program. Funded by the US government, All of Us is working to create the biggest, most-diverse open-access medical database on earth in order to speed up research to improve people's health. Anyone over the age of 18 living in the United States can sign up to join All of Us. Participants volunteer to take surveys and provide samples of blood, urine and/or saliva. These samples are used for laboratory and DNA testing.

In February 2021 Scripps Research, a nonprofit biomedical institute, announced it would distribute Fitbit devices to 10,000 All of Us participants, allowing the team to gather even more data. By syncing their Fitbits to their All of Us accounts, participants will give researchers around the world open access to data including participants' heart rates, physical activity and sleep. To ensure confidentiality, the All of Us team removes names and identifying information from people's data before it is shared. Researchers who use the data must promise never to try to uncover the identities of the individuals who have shared their data with the program.


12-2019
01-2020
2020
09-2020
07-2021

SIX

OPEN SCIENCE IN ACTION

THE PANDEMIC STRIKES

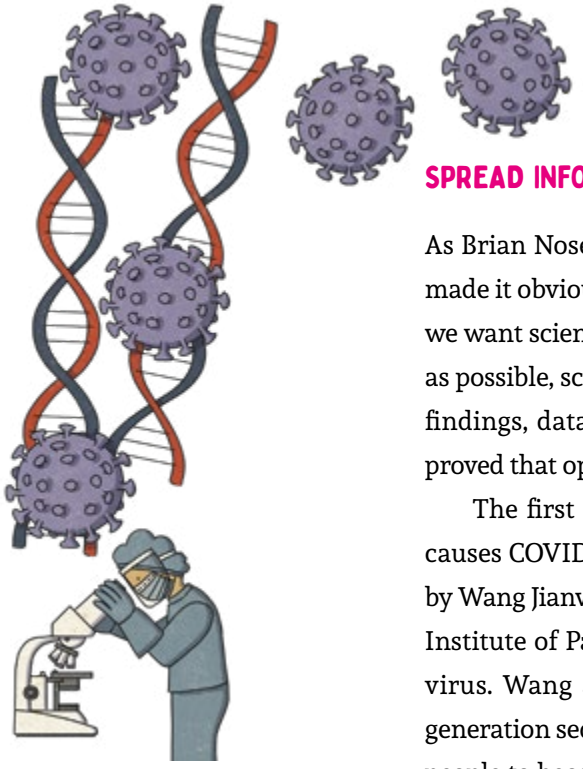
In March 2020 the World Health Organization (WHO) made it official—the outbreak of COVID-19 was a ***pandemic***.

As of November 2022, there have been over 630 million confirmed cases of COVID-19, and over 6.59 million deaths attributed to the disease. COVID-19 shut down not only schools but entire countries. No one was immune.

COVID-19 changed all our lives. It also had a huge impact on the world of science. It proved, perhaps better than anything else could have, that we need open science. That's because, in response to the pandemic, medical scientists in laboratories around the world began working collaboratively to find solutions—and openly shared their findings.

In the early days of the COVID-19 pandemic, many public places were closed for safety reasons.

JANE KHOMI/GETTY IMAGES



SPREAD INFORMATION, NOT THE VIRUS!

As Brian Nosek (whom you met in chapter 1) put it, "COVID made it obvious to everyone that open science is important. If we want science to work as quickly, effectively and efficiently as possible, scientists need to communicate freely about their findings, data and projects." In other words, the pandemic proved that open science works—and that the world needs it.

The first important research into the coronavirus that causes COVID-19 took place in China, where researchers led by Wang Jianwei at the Chinese Academy of Medical Sciences, Institute of Pathogen Biology, sequenced the genome of the virus. Wang and his team used a technology called next-generation sequencing (NGS) to identify the ***pathogen*** causing people to become ill in the city of Wuhan, in Hubei province. The scientists took patients' fluid samples and isolated the DNA and RNA, which allowed them to sequence the genetic material. With that information, scientists were able to construct the entire genomic sequence of the virus. Thanks to that information, they were able to show that SARS-CoV-2 was a new virus, although it was connected to the coronavirus responsible for severe acute respiratory syndrome (SARS).

SCIENCE MATTERS

What's the difference between an epidemic and a pandemic? Both are bad, but pandemics are worse. An epidemic refers to the spread of a disease in a particular region. Pandemics respect no borders—they strike worldwide.

CALLING FOR CHANGE

By January 2020 researchers around the world had begun posting SARS-CoV-2 genome sequences online. Many of these scientists used a popular data-sharing platform called GISAID. But GISAID did not allow the sequences to be reshared with the public. This situation led Rolf Apweiler, co-director of the European Bioinformatics Institute, to call for researchers to post their genome data in databases that are open and place no restrictions on the redistribution of information. In a

letter signed by Apweiler and more than 500 scientists, the group recommended the scientific community "remove barriers that restrain effective data sharing."

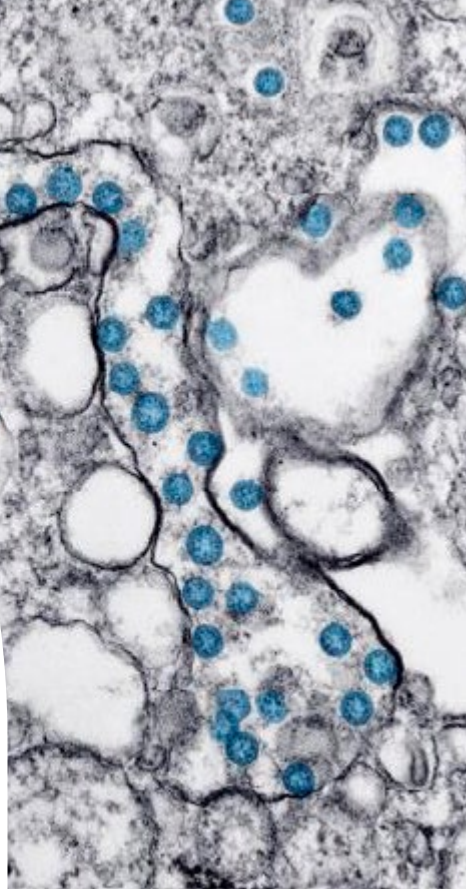
In the same month, Chinese scientists who had sequenced the SARS-CoV-2 genome posted their results online. This information allowed scientists in Germany to develop a screening test, which was shared by the WHO, making the test available to governments around the world.

The solutions medical researchers were looking for included not only diagnostic tests to detect viral DNA but also drugs for treatment—and, of course, vaccines that could protect us from contracting the virus.

NEED FOR SPEED

Prior to the COVID-19 pandemic, it would take 10 years, on average, for medical scientists to develop a vaccine for a new virus. Until the pandemic, the shortest time it had ever taken was four years, back in the 1960s when medical scientists created a vaccine to protect people against mumps, a viral infection that causes swelling in the glands near the ears.

But it took less than eight months for medical scientists to develop a vaccine to protect us from COVID-19. The fact that the virus was so infectious, affecting hundreds of millions of people, made it possible to run huge clinical trials quickly. It helped too that governments contributed funds for research into the vaccine. Open science also helped speed up the development of a vaccine to fight COVID-19.



This photo taken with an electron microscope shows a part of a cell infected with the SARS-CoV-2 virus.

HANNAH A BULLOCK; AZAIBI TAMIN/ PUBLIC DOMAIN

SCIENCE MATTERS

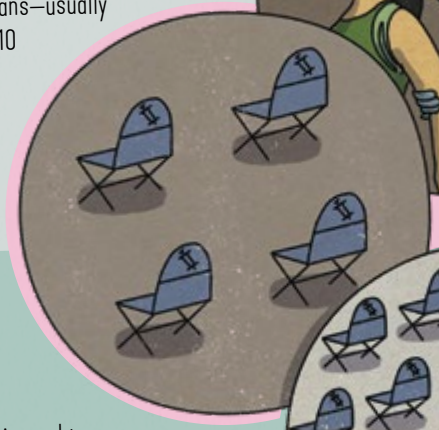
There have been many pandemics in the history of humanity. Between 1918 and 1922, an estimated 500 million people worldwide contracted the Spanish flu. But the Spanish flu didn't start in Spain. It occurred during World War I, at which time Spain was a neutral country and its newspapers were uncensored. Because this allowed the Spanish press to be the first to report on the flu, it was mistakenly believed that the illness started there.

PHASES OF VACCINE DEVELOPMENT

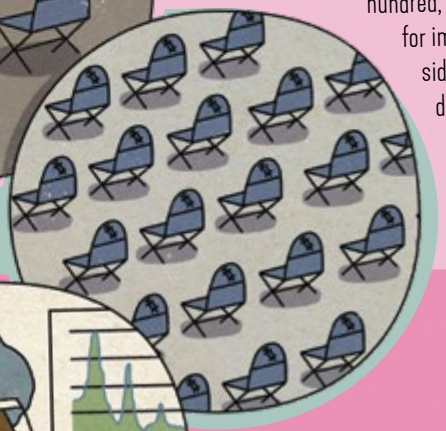
Before it can be approved for use, a vaccine must go through several phases of development. Before the COVID-19 pandemic, each of the following phases could take up two years.

PRE-CLINICAL: The vaccine is tested on animals to see whether it triggers an immune response, indicating that it may work on humans.

PHASE ONE: The vaccine is administered to a small group of humans—usually somewhere between 10 and 50 people.



PHASE TWO: The vaccine is administered to a larger group of humans—usually a few hundred, in order to check for immune response, side effects and dosage.



PHASE THREE: The vaccine is administered to thousands of people. The focus during this phase is to ensure the vaccine is effective and safe.

IMPLEMENTATION: Regulators review the results and decide whether to approve the vaccine for use.

OPEN SCIENCE MUST PROTECT PEOPLE EVERYWHERE

In October 2020 the WHO, the United Nations Educational, Scientific and Cultural Organization (UNESCO) and the UN High Commissioner for Refugees (UNHCR) made a joint appeal to open up science and encourage international cooperation. As UNESCO director-general Audrey Azoulay wrote, "The decision of the United States and many other countries to call for the lifting of patent protection for coronavirus vaccines could save millions of lives and serve as a blueprint for future scientific cooperation. COVID-19 does not respect borders. No country will be safe until the people of every country have access to the vaccine."

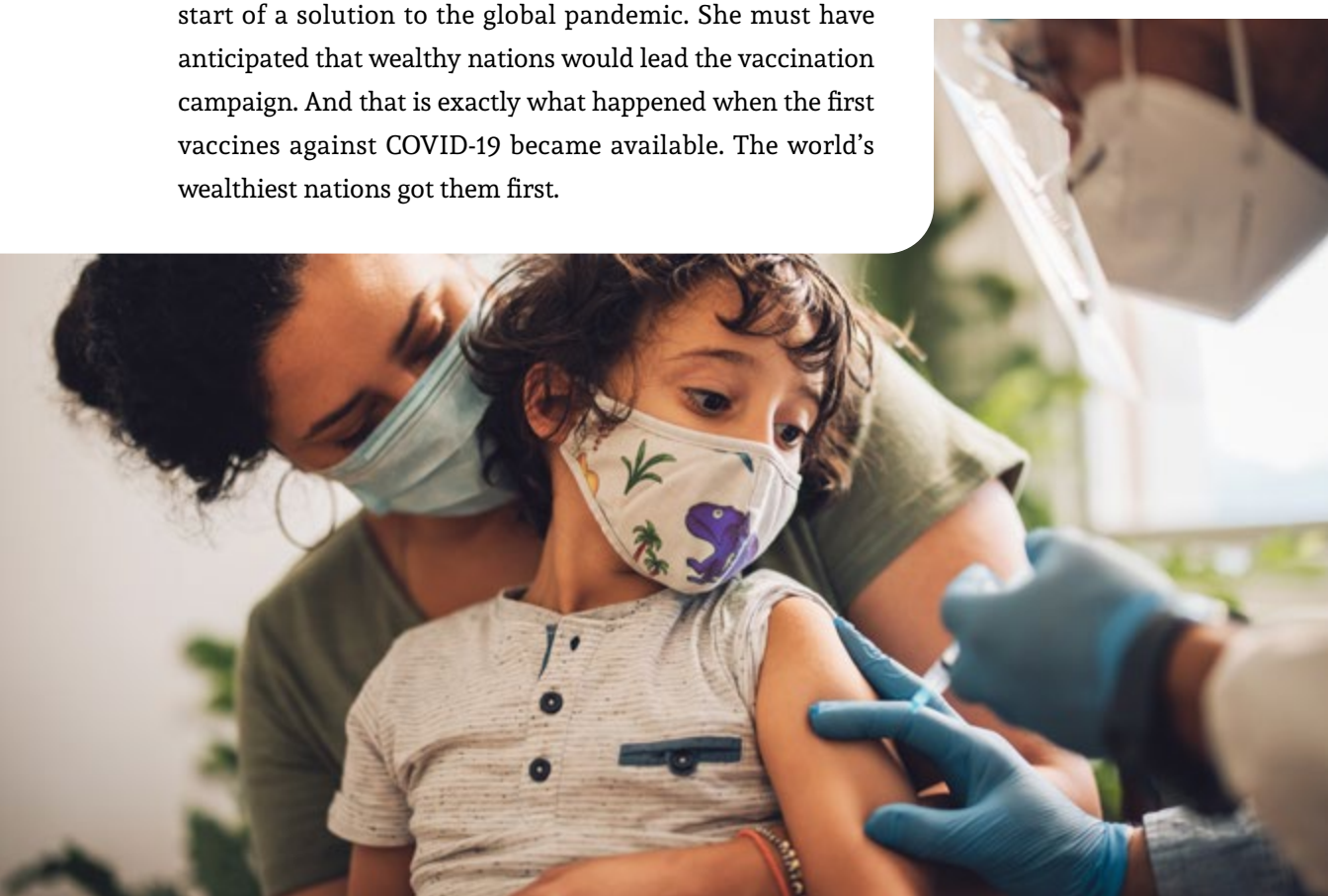
Azoulay understood that developing a vaccine to protect individuals from the ravages of COVID-19 would be only the start of a solution to the global pandemic. She must have anticipated that wealthy nations would lead the vaccination campaign. And that is exactly what happened when the first vaccines against COVID-19 became available. The world's wealthiest nations got them first.

At UNESCO Audrey Azoulay fights to protect the environment, emphasizing that all of society needs to be on board in order to make positive change.

TRUBA7113/SHUTTERSTOCK.COM

In November 2021 the US Centers for Disease Control and Prevention (CDC) recommended that children aged 5 to 11 be vaccinated against COVID-19.

JACOBLUND/GETTY IMAGES



SCIENCE MATTERS

The first Belgian to be vaccinated was then 96-year-old Jos Hermans, a resident of a nursing home in the city of Puurs, where Pfizer's vaccine production facility is located. In Canada, the first person to be vaccinated was an 89-year-old woman from Quebec.

It is human nature to look out for ourselves before we look out for others. The same seems to apply to countries. The wealthier countries in the world wanted to ensure their own citizens were protected against COVID-19 before they shared vaccines with less privileged countries.

Receiving his COVID-19 vaccination meant that Jos Hermans's family could visit him at the care facility where he lives.

BELGA NEWS AGENCY/ALAMY STOCK PHOTO

GET IN LINE!

On December 8, 2020, the United Kingdom became the first country in the world to begin giving its citizens a fully trialed and tested COVID-19 vaccine developed by Pfizer-BioNTech. People living in Belgium were next—they began to receive Pfizer vaccines later in the same month.

SHARING MATTERS

In June 2021 Canadian prime minister Justin Trudeau was in the United Kingdom attending the G7 Summit when he announced that Canada would share up to 100 million doses of vaccine with middle- and low-income nations.

By then the more transmissible Delta variant of the virus was having a catastrophic effect in India, with more than 30.1 million cases of COVID-19 reported in the country at that time.

As of 2022, 12.7 billion doses of vaccine have been administered in 184 countries. In the United States, nearly 70 percent of the population has been twice vaccinated. But too many

In 2021 there was a huge surge of COVID-19 in India. These women are lining up for their COVID-19 vaccinations.

MANOEJ PAATEEL/SHUTTERSTOCK.COM

people living in middle- and low-income nations have not yet had even one vaccine. In these countries, COVID-19 remains a serious threat. Of all the world's continents, Africa has the slowest vaccination rate, with only 31 percent of the population having received at least one dose of the vaccination.

THINKING LONG-TERM

Pedro Valdés-Sosa, the Cuban brain researcher you met in chapter 5, worries about the long-term effects of COVID-19. He points to research indicating that about 15 percent of individuals who contracted the virus will experience long-term

THE ABCs OF VACCINES

All vaccines are based on molecules of the viruses or bacteria the vaccines are trying to fight. The important classes of molecules in all cells are proteins, DNA and ***mRNA***. Historically most vaccines were based on proteins or live harmless viruses similar to the virus causing the illness. These kinds of vaccines take a long time to design and test. New technology has allowed the production of mRNA vaccines that can be produced quickly and tested rapidly. mRNA is short for messenger RNA and refers to the way information from DNA is transferred to create a blueprint for making proteins. Pfizer-BioNTech and Moderna both were able to design mRNA vaccines within days of receiving the openly shared published sequence of the SARS-CoV-2 virus.

ARTUR PLAWGO/GETTY IMAGES

side effects that could affect their lungs, hearts and brains. This situation will impact healthcare systems around the world. But Valdés-Sosa predicted that because of the lack or slowness of vaccine delivery, more people living in middle- and low-income countries will suffer from the long-term effects of COVID-19. "The burden of COVID will be heavier on these nations," he predicted.

The world needs many other vaccines—such as ones that could protect people from diseases like malaria, tuberculosis

Robots are used in the production of large quantities of essential vaccines such as the ones required to battle the COVID-19 pandemic.

WACOMKA/GETTY IMAGES

and pneumonia, which kill millions of people every year. The COVID-19 pandemic has taught us that when scientists from around the world work together and share their knowledge, they can speed up discovery—and save lives. It also reminded us that we do not live in isolation.

We've all been in the COVID-19 pandemic together. And even when it is finally over, we will need to remember some of the lessons we learned along the way. That we must continue working together, sharing information as well as resources, and looking out not only for ourselves but for one another.

CREDIT TK

MAKING THE MOST OF EVERY DOSE

To help ensure that every country in the world had fair and equitable access to COVID-19 vaccines, in April 2020 the WHO, together with other partners, founded COVAX. One of the project's early goals was to support the research and development of COVID-19 vaccines. Once the vaccines became available, COVAX shifted its focus to vaccine distribution. Another COVAX goal was to reduce the risk of wasted vaccines. If vials containing vaccines are stored too long in less than ideal temperatures, they must be thrown away. The same happens if a vial of vaccines has been opened but not all of the doses are used within a certain amount of time. In the world of vaccinology, a 5 percent wastage rate is considered normal. But COVAX was determined to lower this wastage rate by calculating the number of COVID-19 vaccine doses a country would be able to absorb without wasting them. Thanks in part to COVAX's work, lower-income countries have had to dispose of only 0.2 percent (one-fifth of a percent) of their vaccine doses.

Whatever our field of work or study, we can't just think about our own small corner of the world.

FATCAMERA/ GETTY IMAGES

A FINAL WORD

When you think about it, we are all works in progress. Especially kids. But no matter our age, we all try to do better, be better and learn from our mistakes.

Open science is a work in progress too.

As you have learned, open science is based on the notion of sharing. If scientists and medical researchers openly share data and reagents, if that sharing is available to everyone—regardless of where individuals live or the color of their skin or their religion or whether they are disabled or whom they love—we can work together to more quickly find treatments for diseases and make the world a safer and better place for all of us.

THE FUTURE IS YOURS.
HERE'S HOPING YOUR FUTURE—
AND THE FUTURE OF SCIENCE—
IS OPEN.

GLOSSARY

Alzheimer's disease—a brain disease leading to dementia (a decline in memory and thinking and behavioral skills). Most people with Alzheimer's are aged 65 or older.

amyloid—toxic misfolded material in the brain, associated with Alzheimer's disease

article processing charge (APC)—a fee scientists must pay once their work is accepted for publication in a scientific journal. The fee is usually covered by universities or governments.

big science—a style of scientific research developed during and after World War II, when governments in industrialized nations began spending a lot of money on large-scale scientific projects

biobank—a collection of biological samples and clinical information

BRCA genes—genes that, when they mutate, have been proved to cause most cases of inherited breast and ovarian cancers

cell—the basic building block of all living things. A cell has many parts with different functions.

Charcot-Marie-Tooth disease—an inherited disorder that causes nerve damage mostly in the arms and legs

citizen science—public participation in scientific research

cognitive—relating to the mental process of acquiring knowledge, involving intellectual activity such as thinking, reasoning and remembering

colostomy bag—a waterproof pouch that collects waste from the body

contract—a legally binding agreement that usually involves the exchange of goods, services or money

controls—elements that remain unchanged in an experiment or study

Crohn's disease—a kind of inflammatory bowel disease that can cause abdominal pain, severe diarrhea and malnutrition

cyclotron—a particle accelerator invented by physicists

diversity—differences between things. In humans, diversity refers to differences in race, gender, disability, nationality, religion, sexual orientation, age and socioeconomic background.

DNA—deoxyribonucleic acid, the hereditary material in humans and most other organisms that carries the blueprint of how a living being will look and function

equity—fairness

ethics—a branch of philosophy that studies what is right and wrong

evolutionarily conserved brains—brains made up of similar cells, such as those of mice and humans

fecal matter—excrement, the scientific term for poop

genes—the individual pieces of our DNA

genome—all the DNA of one human cell

gentleman scientists—the historical name for scientists who do science in their spare time, as a kind of hobby. Now known as *independent scientists*.

hypothesis—a theory scientists come up with to explain a phenomenon. A hypothesis needs to be tested.

inclusivity—including everyone, describing, for example, a workplace or a field such as science in which no one is left out

infant mortality—the death of children aged one year or younger

informatics experts—people who work with computers

informed consent—permission to take part in something, such as a medical study, having full knowledge of any possible risks

materials science—the study of the properties of solid materials

mRNA—messenger ribonucleic acid, a molecule that carries genetic information

open access—unrestricted, free access to published work. This information can be read, downloaded and distributed to others.

open science—a term first used in the 1990s, referring to the open sharing of data and reagents

optogenetics—the use of light to turn on brain cells and activate neural circuits

pandemic—an outbreak of an infectious disease that spreads across a large region and sometimes the world

patent—a license issued by a government that gives the inventor(s) exclusive rights for a specific period of time to use or sell an invention

pathogen—an organism that causes disease

periodicals—publications that come out periodically; also known as journals

PET scanners—tools for detecting and diagnosing diseases such as cancer, Alzheimer's, Parkinson's and multiple sclerosis

philanthropists—people who donate money to good causes for the betterment of society

plasma jets—streams of energy and hot matter emitted by supermassive black holes

raw data—collected data before it is processed and analyzed; sometimes called *raw score*

restless legs syndrome (RLS)—a neurological disorder characterized by an uncontrollable urge to move the legs

rickets—a condition resulting in soft and weakened bones in children

royalty—a payment for the right to make ongoing use of an asset such as a copyrighted work

science—a way of gaining information about the world through observation and experimentation

scientific journals—periodicals in which scientists report their findings

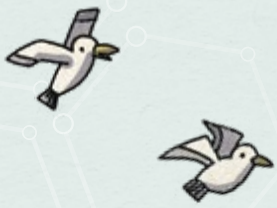
scientific method—the process of collecting data, observing and experimenting with that data to form a hypothesis, testing the hypothesis and, if necessary, adjusting the hypothesis

seismologists—scientists who study earthquakes

spina bifida—a birth defect in which the spine does not form properly

spinal muscular atrophy—a rare genetic disorder affecting the nervous system

STEM—science, technology, engineering and math, all fields that have tended to be dominated by men



RESOURCES

PRINT

Grandin, Temple. *The Outdoor Scientist: The Wonder of Observing the Natural World*. Philomel Books, 2021.

Greenfield, Rob, and Antonia Banyard. *Be the Change: Rob Greenfield's Call to Kids—Making a Difference in a Messed-Up World*. Greystone Kids, 2022.

Kay, Adam, and Henry Paker. *Kay's Anatomy: A Complete (and Completely Disgusting!) Guide to the Human Body*. Random House, 2022.

Kay, Edward. *Germy Science: The Sick Truth about Getting Sick (and Staying Healthy)*. Kids Can Press, 2021.

MacLeod, Elizabeth, and Frieda Wishinsky. *How to Become an Accidental Genius*. Orca, 2019.

Morgan, Ben, ed. *How to Be Good at Science: Technology & Engineering*. Penguin Random House, 2018.

Sisteré, Mariana Tolosa. *The Secret Life of Viruses: Incredible Science Facts about Germs, Vaccines, and What You Can Do to Stay Healthy*. Sourcebooks Explore, 2021.

Stock, Lisa, ed. *Human Body*. Penguin Random House, 2014.

ONLINE

Curious Neuron: curiousneuron.com

Ducksters: ducksters.com

Frontiers for Young Minds: kids.frontiersin.org

Kids Against Climate Change: kidsagainstclimatechange.co

National Audubon Society: audubon.org

National Geographic Kids: natgeokids.com

Patient Innovation: patient-innovation.com

SciStarter: scistarter.org

Links to external resources are for personal and/or educational use only and are provided in good faith without any express or implied warranty. There is no guarantee given as to the accuracy or currency of any individual item. The author and publisher provide links as a service to readers. This does not imply any endorsement by the author or publisher of any of the content accessed through these links.

ACKNOWLEDGMENTS

I could never have written this book without the open sharing from so many experts in the field. Huge thanks to Alan Evans, Katie Corker, Bethzy Gianella Chiang, Nancy Kass, Lynne Krohn, Eileen Meyer, Dan Morgan, Caroline Nickerson, Brian Nosek, Adrien Peyrache, Larry Tanenbaum, Pedro Valdés-Sosa, Astrid Verheusen and Eric von Hippel for taking time out of your busy schedules to answer my questions. Thanks also for your excitement about this project and for believing in a book for kids about open science.

Thanks to the team at Orca Books for encouraging me to take on this challenge. Thanks especially to my editor, Kirstie Hudson, for being so smart, having such good sense and championing this book.

Biggest thanks of all to my partner, Guy Rouleau, who has done so much to promote open science and never says no when I say, “Can I just ask you one question?”

ANSWERS TO "SPOT THE DIFFERENCE" ON PAGE 13

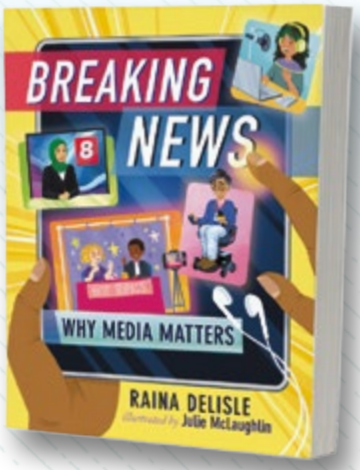
INDEX

index tk

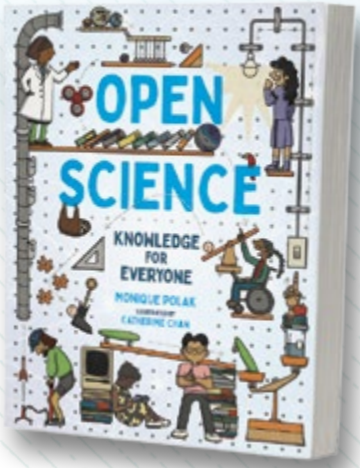
index (continued)

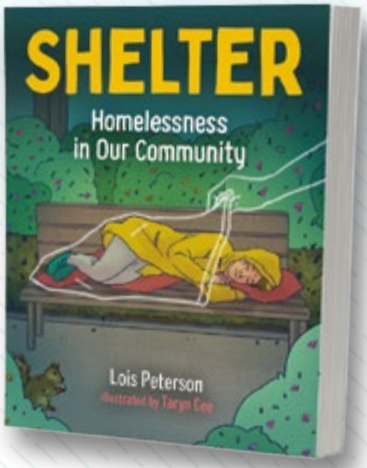
ORCA Think

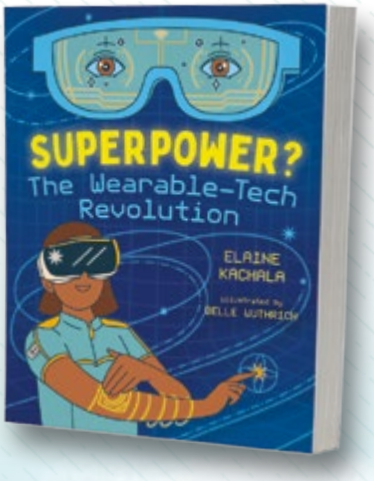
THE MORE YOU KNOW ...

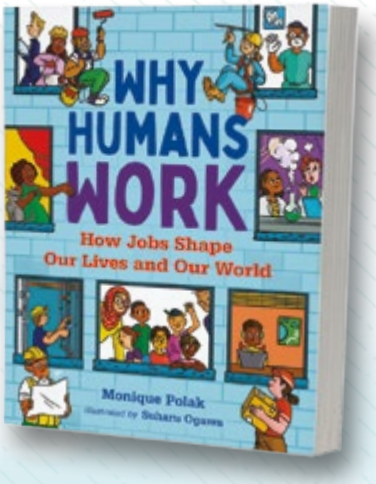


THE MORE YOU GROW









WHAT'S THE BIG IDEA?

The **Orca Think** series introduces us to the issues making headlines in the world today. It encourages us to question, connect and take action for a better future. With those tools we can all become better citizens. Now that's smart thinking!

PHOTO CREDIT: JOHN FREDERICKS

MONIQUE POLAK is the author of over 30 books for young people. She is a three-time winner of the Quebec Writers' Federation Prize for Children's and YA Literature, now called the Janet Savage Blachford Prize. Monique taught for 35 years at Marianopolis College in Montreal. Her previous nonfiction titles include *I Am a Feminist* and *Why Humans Work*.