

# What Is the #WeAreNotWaiting Movement?

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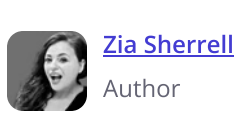


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Millions of people worldwide are affected by diabetes. These individuals must manage their condition through a combination of diet, physical activity, and medication. The movement, known as "We Are Not Waiting," is a network of individuals who have come together to make innovative treatments and technologies available to those diagnosed with this condition.

## Key takeaways:

- The We Are Not Waiting movement comprises hundreds of individuals who use DIY solutions and inventions to better manage their diabetes.
- At the heart of their efforts is an artificial pancreas system, which connects a continuous glucose monitor (CGM) to an external insulin pump.
- Open-source platforms and projects including OpenAPS, Nightscout, and Tidepool, enable users to tailor their diabetes management systems.
- These tools make it easier to track, analyze and monitor glucose levels in real-time.
- As a result, the We Are Not Waiting movement has become a major innovator in the healthcare industry.

Diabetes is a group of serious, potentially life-threatening illnesses that affect how the body uses food and [11% of the United States population](#) is affected by diabetes.

Typically, digestion breaks down carbohydrates into glucose, a type of sugar. Glucose enters the bloodstream and travels to the cells, where it's used for energy. This process relies on a hormone called insulin that allows the cells to take up glucose.

However, in diabetes, the pancreas doesn't make enough insulin, or the cells don't respond properly. As a result, excess glucose builds up in the bloodstream, leading to numerous health problems, such as kidney disease, nerve damage, and vision loss.

Unfortunately, traditional methods of diabetes management can be expensive, time-consuming, and difficult to maintain and access to affordable and effective treatments remains out of reach for many.

Because of these financial and logistical barriers, many people with diabetes are turning to do-it-yourself (DIY) self-management. Continue reading to learn more about the We Are Not Waiting movement and the different DIY technologies available for diabetes management.

## The history of #WeAreNotWaiting

The #WeAreNotWaiting movement was born out of frustration. The hashtag is the call to action of people in the diabetes community who are tired of waiting for traditional research and drug development to provide solutions. Instead, these individuals demand faster access to treatments and technologies to manage their condition without relying on the expensive and often inaccessible healthcare system.

People in the movement share resources, knowledge, and experience to develop novel technologies and treatments and revolutionize diabetes management.

The #WeAreNotWaiting hashtag was first coined in 2013. The same year that two members of the diabetes community — Dana Lewis and Scott Leibrand — decided that they were "not waiting" any longer for major medical device companies to provide the solutions they needed to manage diabetes.

People with diabetes must keep their blood sugar in a healthy range. Typically, this involves using a glucose monitor to test a drop of blood from a fingerstick. Based on the reading, the person then injects an appropriate amount of insulin. Unfortunately, many people require multiple readings and injections daily, and although it works, it's an inconvenient, cumbersome, and costly process.

Lewis and Leibrand wanted to make diabetes management more effective and efficient. Thus, the Do-It-Yourself Pancreas System and DIY movement were born. The pair began experimenting with open-source software and hardware that could automate insulin delivery based on glucose readings from continuous monitors. As news of their efforts spread throughout the diabetes community, others joined in, and the movement rapidly grew.

Today, the We Are Not Waiting community includes hundreds of individuals who share their diabetes management strategies and technologies online. As a result, the group has become a major innovator in the healthcare industry, with countless DIY solutions and inventions to choose from.

## How does automated insulin management work?

At the heart of automated insulin, management is an artificial pancreas system. Lewis and Leibrand designed a "closed-loop" system that connects a continuous glucose monitor (CGM) to an external insulin pump.

A CGM is a device worn on the body continuously that monitors glucose levels in real time and sends data to a smartphone or computer. An insulin pump is an external device that responds to the glucose data by automatically delivering insulin to maintain glucose levels in the desired range. The result is a fully automated process that requires no fingersticks or injections.

Lewis and Leibrand shared their design online, enabling anyone with the knowledge and resources to build their own DIY artificial pancreas system. Other members of the We Are Not Waiting community has made similar efforts, designing more affordable, easier-to-use, and increasingly sophisticated systems.

## Open-source platforms and projects

Numerous open-source platforms and projects have been created by members of the We Are Not Waiting movement. These tools allow anyone to customize their diabetes management systems, from insulin pumps to glucose monitors.

### OpenAPS

[OpenAPS.org](#) was started by Dana Lewis, who made her own DIY artificial pancreas system. Anyone with some technical knowledge can build a DIY system using the information and resources on the website.

Although the device isn't approved by any regulatory bodies, it has proven to be an effective and safe tool for managing diabetes. Now, thousands of people worldwide have built these systems and are using them to manage diabetes effectively.

### Nightscout

[Nightscout](#) was developed by parents and caregivers of children with type 1 diabetes. It's an open-source platform that enables real-time data sharing between a CGM and any device with internet access.

The software allows caregivers to monitor the blood sugar levels of their children in real-time, no matter where they are. So, for example, if a child is at school, the parent can use Nightscout to check their blood sugar levels and ensure they're within a healthy range, providing peace of mind.

### Tidepool

[Tidepool](#) is a nonprofit that has developed an open-source platform to manage diabetes data. It's a web-based, user-friendly system that helps people with diabetes collect and visualizes their data from multiple devices (such as CGM and insulin pumps) in one place.

It aims to make diabetes management easier and more efficient by giving users a comprehensive view of their health. Tidepool also includes tools allowing users to analyze their data and track trends.

The We Are Not Waiting movement has transformed diabetes management by empowering people with the tools to take control of their health.

By providing open-source platforms and projects, they have given users access to more sophisticated systems that enable them to monitor their glucose levels in real-time and make data-driven decisions.

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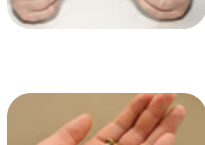
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Penny Min | October 06, 2023

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<p><b>FAMILY HEALTH</b></p> <ul style="list-style-type: none"> <li>Reproductive health</li> <li>Pregnancy</li> <li>Child health</li> <li>Family relations</li> <li>Dental and oral health</li> <li>Show all →</li> </ul>	<p><b>MENTAL HEALTH</b></p> <ul style="list-style-type: none"> <li>Self-care and therapy</li> <li>Meditation</li> <li>Anxiety and depression</li> <li>Eating disorders</li> </ul>
<p><b>LONGEVITY</b></p> <ul style="list-style-type: none"> <li>Longevity supplements</li> <li>Biohacking</li> <li>Healthspan</li> </ul>	<p><b>BEAUTY</b></p> <ul style="list-style-type: none"> <li>Skin care</li> <li>Hair</li> <li>Non-surgical procedures</li> <li>Plastic surgery</li> </ul>
<p><b>NUTRITION</b></p> <ul style="list-style-type: none"> <li>Healthy eating</li> <li>Diets</li> <li>Nutrition for conditions</li> <li>Weight management</li> <li>Vitamins and supplements</li> </ul>	<p><b>FITNESS</b></p> <ul style="list-style-type: none"> <li>Physical health</li> <li>Yoga</li> <li>Pilates</li> <li>Running</li> <li>Injuries and recovery</li> </ul>
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