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Fostering Technological Leaders in Healthcare Solutions

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Human-centered digital healthcare solutions can now be developed for almost anyone on the planet by using their personal health data.

Developers create these plans by gathering customer data. Any sort of data collection raises questions about the most ethical practices, the best ways to store this data, and how to encourage people to give their information. Balancing personalization and trust between users and developers can be a difficult tightrope to walk.

There are proactive ways developers can build long-term trust with service users that will not only create the best healthcare solutions, but retain user loyalty. A company that cares about its customers, welcomes their feedback, and includes them in the design process usually finds its patrons are more likely to stick around.

None of these solutions happen overnight. Here, we highlight ways you can start putting in the work today to create lasting relationships built on a foundation of trust and ethical data handling.

We demonstrate how to best navigate the digital landscape of personalized healthcare solutions, including the most ethical practices for gathering data and ways to make users feel empowered, not vulnerable. Most importantly, we explain how companies can build and maintain customer trust for years to come.

The Ethics of Data Collection for Personalized Healthcare Solutions

Human-centered healthcare solutions are empowering for people who want to take their health into their own hands. This could be anything from tracking their daily steps through an app to seeking tailored healthcare solutions for complex medical conditions.

Users want to be involved in this personalization. They want to feel as though their needs are being considered and addressed on an individual level. The way to do this is by collecting data which can be turned into tangible healthcare solutions for the customer.

This is where ethical data collection, storage, and usage becomes paramount. People are now more interested than ever in a company's ethics, reports Forbes Magazine. Many of us wouldn't even drink beer that's been made by an organization with poor ethics, so why would we trust them with our most intimate personal information?

Benjamin Silverman, Senior Scientific Consultant

at Significo, believes we are growing less guarded about sharing our data. The exception to this rule, he says, is personal health information.

"I think there is a certain degree to which the concept of privacy and the concept of data ownership has evolved in a way that people are actually less concerned about it in 2023 than they might have been 20 years ago," says Silverman.

"We accept that whatever risk there is of a privacy breach is worth it for the convenience of whatever tool we are using. The catch here is that healthcare data, or data about one's personal health status, is exceptional. We still protect it more than other types of data."

This means the bar is extremely high when it comes to making sure that people trust you're going to be a good steward of their data.

The Benefits of Ethically Handling Data

Companies developing personalized healthcare solutions should be embracing ethical implementation. It has long-term benefits which lead to increased customer engagement and trust in a company.

Trustworthy solutions are more likely to have a positive impact on health outcomes. When people feel more confident in their treatment plans they are more inclined to follow them.

Trust is a valuable asset and sets businesses up for long-term success. Ethical implementation leads to increased customer engagement, meaning healthcare solutions are more likely to grow and evolve for the better with this trusted user feedback.

So how can we convince our customers that their data is safe with us and will only be used in a way that benefits them and their health goals?

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The Idea of Informed Consent

Informed consent is the idea that in order to give permission to do something, a person must be fully informed of what they are agreeing to.

For example, it would not be appropriate for a surgeon to perform a procedure on a person by simply asking, "Do you want to have surgery?" and taking their response as consent. The patient must be informed about what part of the body the surgery will take place on, how it will help them, and what risks are involved.

The same applies when gathering health data to develop personalized healthcare solutions. Informed consent is the first step to building trust between developers and users.

"Consent, without being adequately informed, is not consent," says Silverman.

Obtaining meaningful consent can be a challenge, especially in the context of digital healthcare solutions. Topics can be complex and customers must be fully aware of how their data will be used to create these plans before consenting.

There are many ways in which developers can gather meaningful informed consent:

- One of the most important things is to ensure information is in plain English and **easy to understand**. Using plain language and explaining things simply is the best way to achieve this.

- **Multimodal outlets** help cater to a wider audience by giving the same information in different ways. Short videos, interactive quizzes, and long-form articles are all ways of presenting the same information in different formats. People can then choose how they consume this content according to their personal preferences.

- Giving users information that **involves some sort of interaction** can help developers gauge whether their customers are understanding the process. An interactive process with either a chatbot or a human can test to see if someone is understanding.

- Having **community-engaged partners** providing feedback is critical to a successful and ethical design process. Seeking feedback from all potential social groups who are either current users or may become users in the future will not only improve software development for each social demographic, but also foster trust by involving users in the design process.

Informed consent is not only used to satisfy regulatory bodies – it's also a key element to building trust. It shows a customer that the development company has spent time, thought, and sometimes money to gain meaningful consent.

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Inviting Customers to Be Part of the Team

It is human nature to want to feel part of a wider collective. It makes us feel more motivated and connected to those around us.

Clear explanation makes service users feel included and empowered. Yet developers can take more steps to make a customers feel they are actively contributing to the design and implementation process.

The Principle of Solidarity

Those who share their data get the use of an app to personalize their healthcare solutions. What they also receive is the satisfaction of knowing that sharing their data is helping others.

This altruistic element of data donation is a powerful tool developers can use to encourage customers to share their data. It makes them feel good to know they are helping people who may have the same health concerns as they do. It allows them to create a legacy that will live on for longer than any single human will be on this earth.

This idea is called The Principle of Solidarity. For example, in the case of Recco – a health improvement SDK created by Significo – users are given the option to allow Recco to use their personal data to help improve the accuracy of the tool.
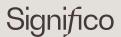
This means that users are collaborating with the tool developers in solidarity with the shared commitment of helping other people build a healthier lifestyle, even if the person donating their data is relatively healthy.

You Get What You Give

Customers feel more confident sharing their data when they are getting something back in return.

Even if the tool simply processes the data and converts it into a more understandable format, this is still something the user feels they are 'getting back' in return for sharing their most intimate information.

"So it might be that you're giving data that's being processed by a digital health tool or algorithm and then you're getting it back in a kind of format that can be used more readily for your health and wellness," explains Silverman.

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Diversity Among Community-Engaged Partners

Another way in which developers can make users feel part of a collective team is by ensuring that they are consulting a diverse range of customers to influence software development. What is considered beneficial to a white middle-class male in his fifties will not always be beneficial in a personalized healthcare solution for a Black woman in her twenties.

Community-engaged partners should represent all social groups. This is especially important for underrepresented populations in this new world of generative AI. All the biases that exist in the algorithms used in this AI create blind spots. If you do not have these members as part of the team, there's a higher likelihood that something will be missed.

Only by gaining the trust of a diverse range of participants can accurate data sets be gathered and used to develop these healthcare solutions.

Educating the Decision Makers

It is not just the app users who benefit from education. Decision makers in the software development world are also in need of education about why it is so important to get users onboard when creating personalized healthcare solutions.

Developers must not only know how best to educate customers, but also educate their own employees on the importance of building user trust. According to Silverman, this value should take precedence over many other business values, aims or principles.

It is not just customers who consider ethics when interacting with a business. Employees value this when deciding whether to apply to or remain at a company. Furthermore, when a company has aligned values, from the CEO to the newest employee, customers are likely to take notice.

Educating the consumer about the use of their data can be time-consuming and move at a snail's pace. Building trust does not happen overnight and dedicating the time to have that conversation with users is a huge undertaking, one that many researchers may not be prepared for at the outset.

Silverman explains the push and pull effect between time efficiency and building trust.

"There might be people who say, 'That's bad for our business, that takes time,'" he says. "I do think you have to start from a standpoint of educating business leaders about why this is important.

"It's important for two reasons. One is that it's just the right thing to do. And we should do the right thing, even if we have a choice not to. And the other is, ultimately, if you don't do it and you don't have that trust with your users, it puts a limit on what you're going to be able to do to help people," says Silverman. "If you don't have good ethics, you don't have a good business."

The Balance of Personalization & Trust

It's no secret that the stakes are extremely high when it comes to the use and misuse of data. Loss of trust could be disastrous and some companies may never recover.

Bespoke healthcare solutions cannot be developed without personal data. The more data collected, the more accurate the healthcare plans can be. With this comes a huge responsibility to maintain user trust by keeping their data out of unsafe hands.

Decision-makers must implement robust security measures to protect this data from cyber threats and unauthorized access.

There are enormous financial implications for any company that causes a data breach.

Decision-makers must implement robust security measures to protect this data from cyber threats and unauthorized access.

Perhaps worse, this company will also lose its customers' trust, which is something that may take much longer to bounce back from.

Thankfully, there are things you can do to safeguard against total loss of trust should a data breach happen.

"If there's a data breach or something goes wrong, if you have already had a conversation with people about what the risks are, why you're doing it, and how you're handling their data, it's much easier to recover from than if you're just taking people's data and not fully educating them, informing them or building that trust," says Silverman.

Nobody wants a bad thing to happen, and people will always be upset if their data gets lost. This trust factor can make a big difference to a company's relationship with its service users.

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The Future of Personalized Healthcare: How to Stay on Top of the Trend

So how can we remain at the forefront of creating personalized healthcare solutions in the most ethical way possible?

Ethically speaking, the parameters do not change all that much. The most ethical way of gathering data is to make sure people are fully informed about why they are handing over their data. They must have autonomy over how much data is used and what it is used for.

The ethics of data collection for healthcare solution software is easy to keep up with: we just have to keep reminding ourselves of how to handle this data properly. Regulations, of course, will change, and it is critical developers understand the legislation before implementing new data procedures.

Having good legal and regulatory counsel who are experts in this area of law is always a plus. Simply reading the news and keeping up to date with fresh guidelines is also advised.

In this exciting digital age, there are always new ways of protecting data, encrypting data, and making new synthetic data which companies can use to ensure their users' data is safely under lock and key.

Striking this balance between creating personalized healthcare solutions and fostering trust is possible when businesses are prepared to lay the foundations that will maintain this

trust for the long-term future.

As demonstrated here, there are a multitude of ways of building trust which go hand-in-hand with ethical practices. Building deep-rooted relationships with customers and employees is key. Those handing over their data want to feel represented, included in the design process, and want to get something back that makes sharing their personal data worthwhile.

At the forefront of this ethical software development is cultivating user trust, which encourages these users to work with the developers. This way, we see the Principle of Solidarity in action.

These community-engaged partners should have access to information in multi-modal formats to ensure it is fully understood and must be representative of a whole cross-section of society.

The practice of gathering informed consent also gives users the power to ask questions and withdraw consent at any part of the process. This creates a human-centered approach that is tailored to each individual's comfort level.

By getting informed consent, developers can work ethically to improve their relationship with those who will be relying on these healthcare solutions for years to come.

Significo has the tools to remain at the forefront of ethical data collection.

Like and follow us on social media to stay informed of the latest health and data trends.

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