

Frequently asked questions about personalised healthcare



What is personalised healthcare?

Personalised healthcare involves tailoring care to a person's unique health needs. It refers to developing an appropriate and timely individual care plan for a person affected by [insert condition here/a condition], taking into account treatment and diagnostic options, and also lifestyle, personal characteristics and circumstances.¹

What does personalised healthcare mean for me, as someone living with [insert condition here]?

Personalised healthcare affects many different parts of the healthcare system, which could in turn affect you, including:

- Improving research into new medicines so that they are more effective.²
- Using new technology to deliver your care in a more convenient way, including continuous monitoring and giving you reminders to follow actions agreed in care plans.³
- Detecting and diagnosing conditions more quickly and comprehensively, by using tools to identify factors associated with specific conditions.⁴
- Increasing engagement with healthcare professionals, for example through digital consultations, to deliver more of what you need.⁵
- Better prediction and prevention, as data can be used to identify those most at risk, and you can develop lifestyle approaches with a healthcare professional.⁴

All of these have many potential benefits for your health, quality of life, and how empowered you feel to manage your condition, but also, for society as a whole.

What does personalised healthcare mean for me, as someone caring for a person living with [insert condition here]?

Personalised healthcare creates a more collaborative relationship between people affected by a condition, professionals and the health and care system.¹ As someone caring for a person living with a condition, you can:

- Work with their doctor to develop an individual care plan. This can include more appropriate and timely personalised treatment options (if available), but also tailoring all care to the person's lifestyle and circumstances.¹



FAQs about personalised healthcare



- Use new technologies (if available) to help monitor their condition and deliver care in a more convenient way.³
- Share your experience and perspective to improve care not just for people living with a condition, but for those who care for them too.

What should I ask my doctor about personalised healthcare?

Personalised healthcare is evolving all the time, across different geographies and health conditions. If you want to explore personalised healthcare for yourself, or someone you care for, a good place to start is the status of personalised healthcare in relation to yours or their personal circumstances. For example, whether personalised healthcare is a viable option for the condition.

Here are some initial questions you may find helpful to ask your doctor:

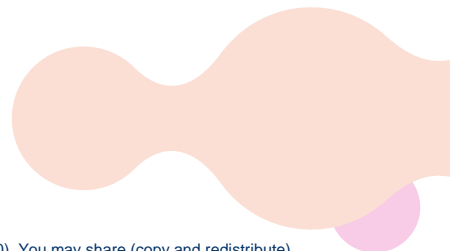
- Is there any genomic testing available for this diagnosis?
- Are there any targeted treatments available for this condition?
- Are there any new clinical trials that offer a more targeted treatment for this condition?
- Are there any apps or other digital tools that can better monitor the progression of the condition?

You can find a glossary of definitions related to personalised healthcare [here](#)

What is the difference between personalised medicine and personalised healthcare?

Personalised medicine refers to a treatment approach that uses genomics to understand a person's condition, and treat them specifically.^{4,6} Personalised healthcare is broader than just treatment. It provides care by first and foremost looking at the person, their lifestyle and their circumstances, and finding the most effective way to care for them.¹

It provides more sustainable diagnostic support and appropriate and timely treatment approaches through an individual healthcare plan.⁷



FAQs about personalised healthcare



How can personalised healthcare help people with conditions where there are currently no treatment options, for example in their daily life at home?

Advances in technology can improve the day-to-day management of a condition, for example by giving reminders to take medicines or log symptoms. It also allows people to speak to their healthcare professionals and access their health records securely from their own homes.^{3,8}

This can help people to better understand their condition, give them more of a say in their care plans, and find habits that have the potential to improve their quality of life. Personalised healthcare and improved monitoring can provide information that helps research and, as a result, helps to advance the search for new treatments, leading to better care decisions.^{2,5}

FAQs about the future of personalised healthcare

When will personalised healthcare become a reality?

Personalised healthcare is already a reality in many ways, with advancements happening every day. These developments can be seen with the availability of more targeted treatments, such as precision medicines; diagnostic tests, such as comprehensive genomic profiling, also known as biomarker testing; and imaging, such as visualising progression of a condition and how treatments are working.⁴

However, there is still a long way to go before it becomes routine for every person living with a condition to be treated individually with a unique health profile that results in a personalised healthcare plan.

Will personalised healthcare replace healthcare systems as we know them?

Personalised healthcare has the potential to fundamentally change the way current healthcare systems operate, lowering the cost of healthcare and making each step in a person's treatment more efficient. It has the potential to transform healthcare systems towards paying for healthcare that provides the outcomes that mean the most to people affected by conditions.^{7,9}



FAQs about the future of personalised healthcare



How will personalised healthcare help to improve treatment?

Personalised healthcare puts the *person* living with a condition at the centre of the process, instead of the *condition*. It looks at lots of factors such as demographics, general health, unique genomics and individual needs to find the best care for that person. Taking all of these factors into account means that a timely and appropriate care plan is matched to each person individually, which has the potential to improve their outcomes.^{1,4}

Another big focus of personalised healthcare is to engage more with people affected by conditions and patient organisations when developing new medicines. They are consulted during clinical trial planning to ensure research is focused on developing new treatments that meaningfully help the people who need them.^{2,10}

How will personalised healthcare help to improve diagnosis of conditions?

Personalised healthcare involves advances in technology, such as imaging techniques, which can find out more about a condition and what is going on inside the body, and other diagnostic tools, such as genomic profiling (or biomarker testing), which can reveal more about the factors based on our genes influencing the condition.^{3,4}

Using these new technologies, there is potential for conditions to be detected earlier and/or prevented, and physicians can make more informed care decisions and provide personalised treatment plans.⁴

How will personalised healthcare help to improve prediction and prevention of conditions?

A big part of moving towards personalised healthcare solutions focuses on early detection, screening and follow-up to predict and prevent conditions:

- With the consent of the people sharing it, data can be used to identify those most at risk of a condition so that suitable lifestyle changes can be agreed between the person affected and their healthcare professional.^{1,3}
- Recognising early symptoms means people can communicate these to a healthcare professional and access healthcare early on.¹¹
- By tackling individual risks early on, people can continue life with minimal disruption and potentially limited long-term consequences.^{11,12}

This has the potential to move society as a whole from 'treating conditions' to caring for the individual as a whole and taking into account their specific needs.

FAQs about data and new technologies in personalised healthcare



Why are people asked to share their data to inform personalised healthcare?

By consenting to sharing their data and insights on management of their condition, people can contribute to broader knowledge and understanding of a specific condition.¹³ Information that could identify individuals will be removed from data sets, so that the people whom the data describe remain anonymous.

Artificial intelligence, telemedicine (e.g. telephone consultations) and digital health apps, as well as other tools that can gather data, with consent of the individual, have the potential to make healthcare more tailored. They can increase interactions with healthcare professionals, and help with tracking or monitoring a condition on an ongoing basis. This can in turn lead to more personalised decision-making, that has a positive effect on people's lives.^{5,13,14}

Bigger and more robust data systems, such as electronic health registries, containing individuals' health data, can measure the impact of healthcare and monitor a person's health status including compared to others affected by the same condition. They can also generate wide-scale data that contribute to improving overall understanding of a condition, and benchmark progress made.^{8,13}

How will sharing data benefit me and others living with [insert condition here]?

Monitoring your condition and sharing data can allow you to engage more with your healthcare professional, working together to tailor a care plan that is specific to you and your needs. Long-term, data sharing can help researchers learn more about specific conditions, and develop more targeted treatments or methods for you to manage your condition in day-to-day life.¹³

Where are these data kept? Will they be safe?

When agreeing to provide data to a third party, consent should always be asked for in writing, with detail about how data will be kept and their primary use. The third party should confirm what data will be collected, whether it will be anonymised, who will have access to the data, and the protocol for removing data from their records.

Data collected for research, for example, may be used for more than one research project, but the details of this may not be specified.

Is it legal for companies to collect data to inform personalised healthcare without consent?

No, personal data cannot be collected and used without the person's consent. There are strict guidelines in place, such as the EU General Data Protection Regulation (GDPR), which ensure any data collected and used by an organisation is only done so with the person's consent.

FAQs about data and new technologies in personalised healthcare



How are genomic tests done? Will we have to get our own tests done?

Genomic testing is a key part of personalised healthcare for many conditions and can help to develop a personalised healthcare plan.

Genomic testing involves looking at someone's DNA: the chemical database that carries instructions for our body's functions. DNA is typically collected from saliva, either by spitting into a tube or swabbing the inside of your cheek.¹⁵

It will usually be done as part of a genomic consultation with a doctor. A medically trained professional will order and do the test. If you are interested in genomic testing, you should speak to your healthcare provider and insurer (if appropriate) for more information about your options.

FAQs about getting involved

How do I find a clinical trial that is looking into more personalised treatment and approaches?

The availability and frequency of clinical trials varies across geographies and conditions. If you or a person you care for is interested in participating in a clinical trial, then the best approach is to speak to your healthcare team or local patient organisation [**personalise as applicable**] to gain more insight into any relevant trials that may be recruiting.

How can I get involved in advancing personalised healthcare?

The easiest way to help advance personalised healthcare is to spread the word. There are still so many people living with conditions that are not aware of all of the options available to them in making their care more tailored. By educating other people about personalised healthcare, you can empower someone to ask for care for themselves and their loved ones.



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