Personalized Medicine: How to Evaluate Health Information Online

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Abstract

You may have come across the term “personalized medicine” before, but what is it? Genetic testing has become commonplace for investigating ancestry and disease risk. There are a myriad of genetic tests available for sale online claiming to offer meal plans and exercise routines tailored to your genetic code. After all, what could be more personalized than DNA? As health information has become more accessible online, another question arises: what information is reliable and what is not? This open educational resource explores 6 questions that can be used by anyone to evaluate the trustworthiness of online health information: Who runs the website? What is the website about? Where are the sources of health information? When was the website last updated? Why was the website made? How is the website funded? Asking these questions is key for the public and medical professionals alike.

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Abstract

You may have come across the term “personalized medicine” before, but what is it? Genetic testing has become commonplace for investigating ancestry and disease risks. There are a myriad of genetic tests available for sale online claiming to offer meal plans and exercise routines tailored to your genetic code. After all, what could be more personalized than DNA? As health information has become more accessible online, another question arises: what information is reliable and what is not? This article explores 6 questions that can be used by anyone to evaluate the trustworthiness of online health information: Who runs the website? What is the website about? Where are the sources of health information? When was the website last updated? Why was the website made? How is the website funded? Asking these questions is key for the public and medical professionals alike.

Article

Personalized medicine is about prescribing the ideal drug and dose according to a patient's genetics. Optimal drug therapy is determined by two components: maximizing drug efficacy (how well the drug works) while minimizing adverse drug reactions (negative side effects) [1].

Standard medicine follows the blockbuster pharmaceutical model that “drugs should be developed for as many people as possible so as to achieve sales of at least US$1 billion,” [2]. On the other hand, personalized medicine seeks to give the right drug at the right dose for the right patient [3].

Through blockbuster medicine, drugs may be prescribed based on factors such as a patient's age, weight, sex, and disease condition. But what’s not considered are genetic variants, which can have a multitude of effects on the efficacy of a blockbuster drug. Depending on the variant, a patient may require a higher or lower dose than the standard due to how they metabolize the drug. Drug metabolism determines what the standard dose of a drug should be depending on how long it takes an average patient to clear the drug—i.e., how long a drug takes to pass through their system.

To identify genetic variants a patient may have, genetic testing is required. Without genetic testing, patients may be in danger of feeling no therapeutic effect, overdosing, or having an adverse drug reaction to standard doses of a drug. It’s no small risk—blockbuster medicine leads to over 1 million adverse drug reactions a year in the US alone [4].

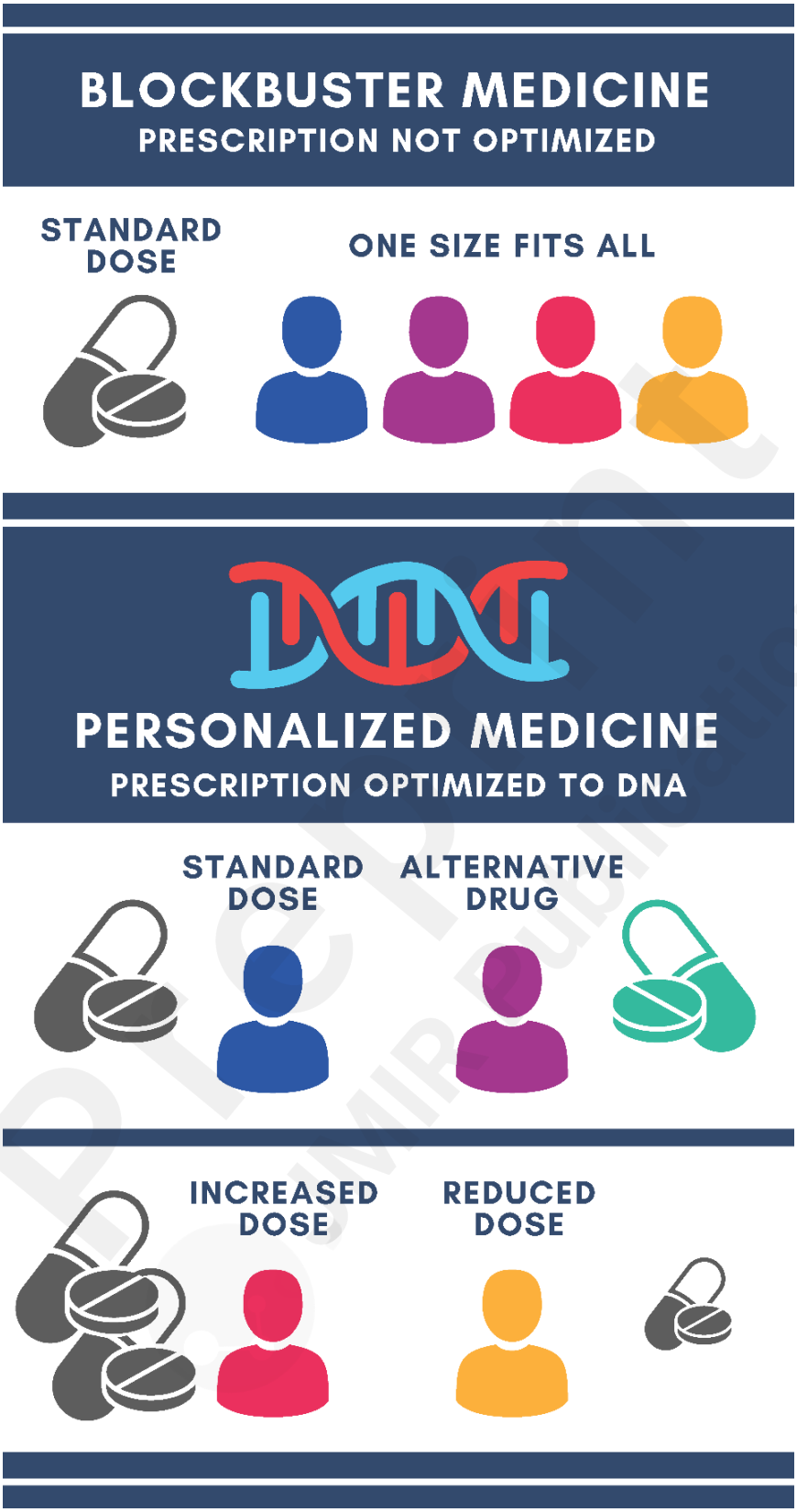

Figure 1: *Blockbuster vs. Personalized Medicine. The practice of blockbuster medicine is to prescribe a standard dose for all. Personalized medicine instead optimizes the prescription based on genetics, identifying whether a standard dose, increased dose, reduced dose, or alternative drug altogether will maximize drug efficacy and minimize adverse drug reactions.*

In contrast to blockbuster drugs, personalized medicine allows the precision to prescribe drugs based on a person's genetics (**Figure 1**). This specificity towards optimization is the future of healthcare

and has become steadily more affordable as DNA sequencing technology advances, with some organizations now offering the $100 genome [5].

Not only is the technology of genetic testing advancing, so is its utility. Genetic testing is often associated with healthcare purposes such as genetic disease testing, to diagnose a patient with a genetic disease or to assess hereditary risk for genetic disease from family health history. Clinical genetics tests are ordered by healthcare professionals, but direct-to-consumer genetic tests are available in the public market, and include tests for personalized medicine. Along with health purposes, direct-to-consumer genetic tests can be used to test for ancestry or for “recreational” purposes, such as to see if you are likely to find cilantro to have a soapy taste, or genetically predisposed to be a night owl [6].

In the digital age, with so much information at our fingertips, it can be a challenge for both the public and medical professionals to distinguish between what is reliable health information and what is not, particularly regarding easily accessible direct-to-consumer genetics tests. In fact, in a recent survey of healthcare professionals in the UK by the Patient Information Forum (PIF), 58% reported difficulty sourcing reliable health information to share with patients [7].

The following sections explore six principles for assessing online health information about personalized medicine that can be used to evaluate if a website’s information is credible and trustworthy.

HOW TO EVALUATE ONLINE INFORMATION ON PERSONALIZED MEDICINE

Evaluating the reliability of a website is a multi-step process, but don't feel overwhelmed. Go through the following questions one at a time. The concerns or reassurances that these questions raise will help you in how to approach the health information on personalized medicine you find online.

Questions to Ask	Examples of What to Check
Who runs the website?	● “About Us” or “Contact Us” section ● Founding organization ● Website domain ending (.com, .gov, .edu)
What is the website about?	● Key terms (e.g., pharmacogenetics or pharmacogenomics)
Where are the sources of the website?	● References ● Peer-review ● Expert qualifications and track

	record
When was the website last updated?	• “Last Updated” or source code
Why was the website made?	• “Mission Statement” or “About Us” • “Privacy Policy”
How is the website funded?	• Company • Industry body • Advertisements • Charity Navigator

Table 1:
Questions to ask and points to check for when evaluating the reliability of a website’s health information.

WHO RUNS THE WEBSITE?

Is the website created by an individual or an organization? Most reliable personalized medicine websites require a team of experts to work on them due to the depth and breadth of information and the work it takes to keep it current. Look for an "About Us" section on the web page. A detailed version of this page could include a list of team members with their photos, positions, education and certifications, and a short biography. There may also be a separate "Contact Us" section. A lack of information on the creators of the website and no method to contact them is a sign of unreliability. Part of presenting reliable health information online means standing by that information with your name. If no one has claimed ownership of the website, it may be because the creators don't want to associate their names with it, which is not a sign of quality information.

If an organization runs or is associated with the website, look up their credentials. Perhaps they are a government organization, which lets us know the website is up to government standards. Check the ending of the website’s URL for the official government domain of your country, such as .gov for the US or .gov.uk for the UK. Perhaps the website operators are a private organization, in which case some further research is required to assess their standards. One way of doing this is to look up the organization's rating through the Better Business Bureau [8].

WHAT IS THE WEBSITE ABOUT?

Websites about personalized medicine can cover a variety of topics. They could give an overview of the subject, or they could focus on cutting-edge developments. A website could be as specific as being about a single drug or single genetic variant. Current research is expanding in two directions: what effects a specific genetic variant has on drugs (pharmacogenetics), and how a specific drug is affected by genes (pharmacogenomics) [1]. Pharmacogenetics allows for prescriptions to be personalized to what will be most effective, based on the patient’s genetics. Pharmacogenomics allows medical researchers to see the variation of responses to a drug in the population [9]. Currently, there is more information on pharmacogenetics as it is simpler to determine how a genetic variant affects drugs by identifying what drug pathways the genetic variant is involved in. Pharmacogenomics, on the other hand, is more complex as there are still unidentified genetic variants that can affect a drug's efficacy and side effects. Does the website state if it has a pharmacogenetic or pharmacogenomic focus? If neither of these terms are found, then the website is lacking in key vocabulary related to personalized medicine. This indicates that the information found

on the website may be limited.

WHERE ARE THE SOURCES OF THE WEBSITE?

Reliable health information is generated through the scientific process and findings are published in peer-reviewed journals. Some of these findings are reported in the news but often with misleading headlines. For example, they may report: "Scientists Find Cure for Cancer!" A more accurate description may be that in experimental trials under a certain set of conditions, scientists found that a drug shrinks tumors in mice by a statistically significant amount when compared to a placebo. And it is still only about mice, and not of direct utility for near-term use in personalized medicine. While this isn't as attention-grabbing, it's incremental findings like these that scientific progress is built on.

Information about personalized medicine is particularly reliant on clinical trials where drugs are tested. Even an unreliable website may provide sources, so don't let your evaluation end there. Identify where these references come from: are they directly from a peer-reviewed scientific paper? Or are they from a news article or press release paraphrasing scientific findings? A reliable website will provide references and report its health information from a direct source.

Another aspect of location is to identify the country or jurisdiction in which the website is located. Organizations in different countries will be following different regulatory codes and medical practice guidelines. Does this information apply to you in the country where you live?

WHEN WAS THE WEBSITE LAST UPDATED?

Personalized medicine is a rapidly advancing field. For this reason, it is important that websites about personalized medicine are kept current, at least within the last 5 years. In some cases, this might mean revising or updating information. However, not all information may need to be changed (for example, a page on the origins of personalized medicine). Even if the information remains unchanged, a feature of a reliable website is to include a date of when the page was last reviewed. If given, dates can usually be found at the bottom of a web page or in the comments of the source code. If there is no date to be found, ask yourself: are you comfortable relying on undated health information?

WHY WAS THE WEBSITE MADE?

Broadly, websites are either made to sell something or to inform about something. Try to determine with what purpose the website was made and who the website is for. Sometimes this can be found directly under a heading like "Mission Statement". If there is no express motto, then assess the website's homepage and "About Us" section. A website on personalized medicine can have a diverse audience, but likely it will be aimed directly at a particular group. In this field, that is either scientific researchers, healthcare professionals, or healthcare consumers—i.e., the public. It’s important to identify the target audience of a website as each of these groups are looking up personalized medicine for a different purpose.

Scientific researchers aim to advance the field of personalized medicine. They are looking for information they can use in their studies such as the identification of genetic variants and their clinical significance. Healthcare professionals are looking to apply personalized medicine in their clinical settings. They may wish to order a genetic test for their patients or write a prescription using knowledge of personalized medicine to determine the particular drug therapy or dosage. Healthcare

consumers and patients are looking to learn more about personalized medicine and possibly receive genetic testing. This can be especially true if they have a family history of unusual reactions to certain drugs.

Depending on the purpose of the website (for example, a discussion forum), it may require you to register to access the website. Even if there is no registration required, there may be an option to sign up for a newsletter. Websites can present a number of ways to ask for your personal information. Look for a "Privacy Policy" section that declares how your information will be used. Weigh how you feel about sharing your information to access the website or its resources.

HOW IS THE WEBSITE FUNDED?

All websites require financial support to keep online, current, and growing. Common forms of revenue for websites are through sponsor organizations or through advertisements. Some websites may be ad-free, but if they are not, a sign of reliability is for the advertisements to be clearly labeled as ads. A more insidious form of advertisement is to disguise the ad—for example in the form of a biased article or "expert" recommendation on the product. If a product is strong enough to stand on its own merit, then there should be no problem in labeling advertisements as such. A hidden advertisement is both an underhanded tactic and indicates a product of poor enough quality that it requires deception to sell.

Some websites on personalized medicine may be supported by charity. They may or may not be open to donations online. If they are and you wish to donate, first look them up through a website like Charity Navigator [10]. Charity Navigator is an organization that assesses charities for legitimacy. Their ratings give insight into a charity's transparency and accountability.

Personally evaluating the health information websites you visit will help hone your sense for finding reliable information. Fortunately, there are also outside resources that can help with your evaluation. In the UK, since 1997 the Patient Information Forum (PIF) offers the PIF TICK as a checkmark of quality for health information that has been assessed to be trustable [11]. Internationally, founded in 1995, Health On the Net was an organization that evaluated online health information according to its code of conduct (HONcode) but became permanently discontinued in 2022 [12]. Evaluating the credibility of health information online has been paramount since Internet use became mainstream, which is why a number of evaluation systems date back to the 1990s. However, it is vital that an evaluation system evolves with its platform, as digital health information today is no longer spread through only websites but also social media and e-learning.

Part of evaluating health information online is familiarity with how health information is presented. The U.S. National Library of Medicine allows an opportunity to practice by providing a tutorial with sample health websites to evaluate [13].

The questions raised in this article are fundamental points to look out for when evaluating the reliability of health information online. But the principles you've learned will apply even here: note that the article is free to access and has been peer-reviewed. Check when it was published and explore through the references yourself. Take care and you will find there is a wealth of information available on health that you too can investigate by asking the journalistic questions: who, what, where, when, why, and how.

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Supplementary Files

Figures

Blockbuster vs. Personalized Medicine. The practice of blockbuster medicine is to prescribe a standard dose for all. Personalized medicine instead optimizes the prescription based on genetics, identifying whether a standard dose, increased dose, reduced dose, or alternative drug altogether will maximize drug efficacy and minimize adverse drug reactions.