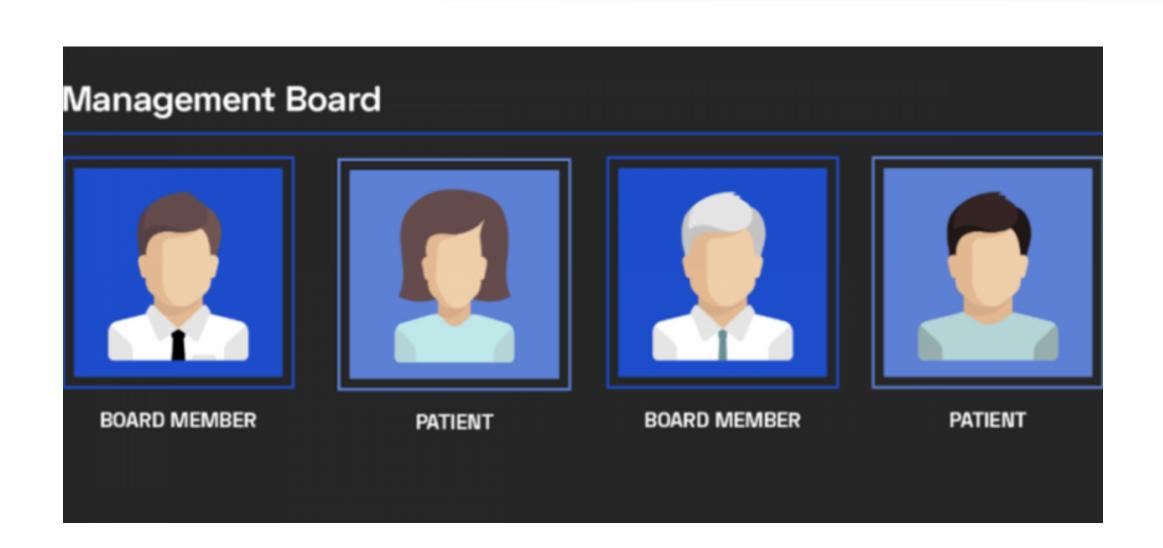
Journal of Medical Internet Research | Importance of Including Patients in Designing Care

On September 6, 2022

Tagged digital health, Empowerment, Engagement, Future, Involvement, Participation, Participatory, Patient, patient centered, patient centric, patient design, patient focus, user design



JMIR Publications published "Patient Design: The Importance of Including Patients in Designing Health Care" in the Journal of Medical Internet Research, which reported that patient design, instead of patient centricity, should lead healthcare leaders in designing products, facilities or technologies for patients.

Importantly, the paper is co-authored by a physician and a patient. Dr Bertalan Meskó, MD, PhD, Director of The Medical Futurist Institute, and "e-Patient Dave" deBronkart, a leading voice in the global e-patient community shared real-life examples in their paper to emphasize the importance of patient design.

Authors argue that healthcare in the 21st century has been going through a paradigm shift, as defined by Thomas Kuhn in his 1962 classic, *The Structure of Scientific Revolutions*. Yet the model under which clinicians are trained, care is conducted, and care delivery is designed, has not changed significantly even though we call it "patient-centered."

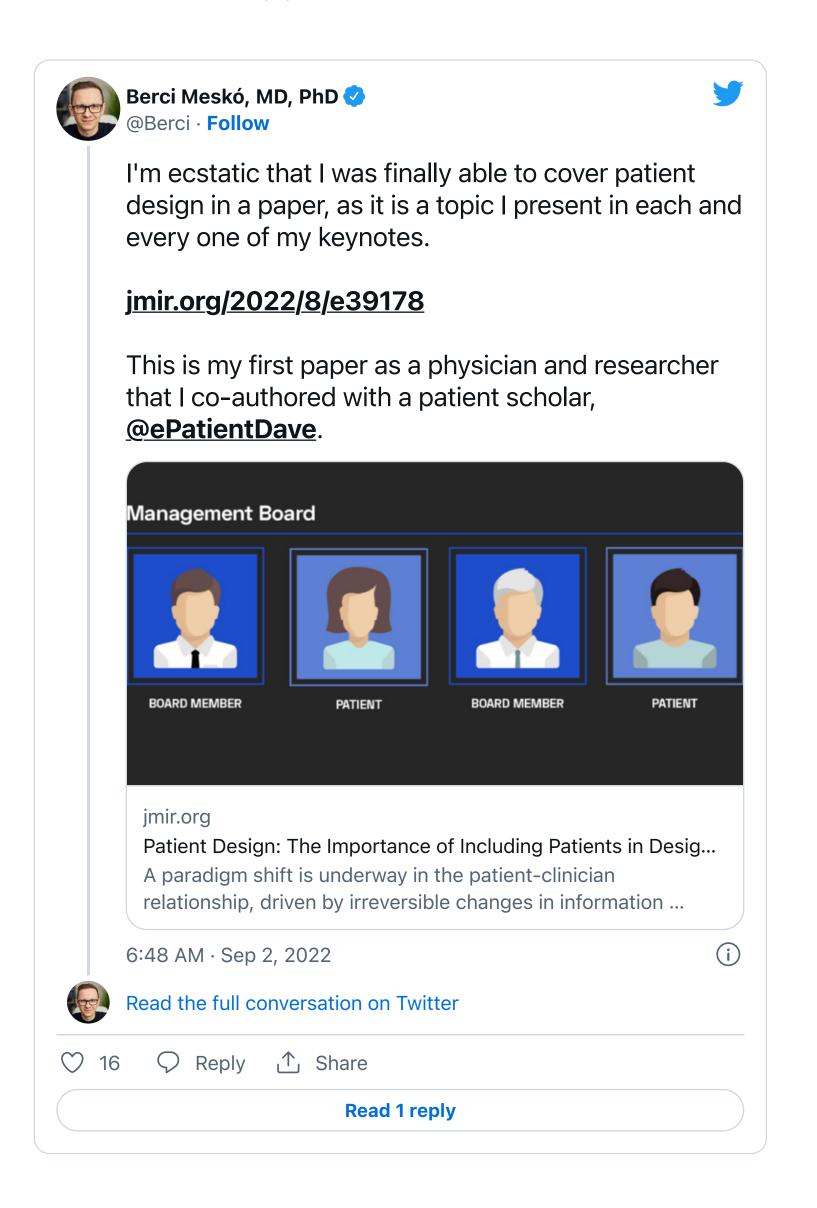
The rise of the internet and digital health led to the end of that era.



From joining patient communities online to using a range of digital health sensors, patients bring new value to the table. For example, the #WeAreNotWaiting movement is a community of people with diabetes taking disease management into their own hands, organizing themselves, and developing applications, platforms, and other solutions to help each other. They created the open source "DIY pancreas" software that automatically provides patients with the right doses of insulin based on their blood glucose level. The software was created entirely by the patient community with no contribution from medical professionals. Significantly, it is the second most-forked app on GitHub, because each user can tweak it to suit their own body and their own preferences. *That* is real patient power: the ability to take care into their own hands.

The authors concluded in their JMIR Publications Research Output that we are at the end of the period in history where physicians know important scientific facts and medical insights that patients can not.

Before 1900, doctors in medical school were not even exposed to patients, yet by the end of the 20th century, the internet let knowledge flow. Now in the 21st century, a plethora of personal health devices give patients access to more information than their physicians have.



The possibility of true participatory medicine is on the horizon—patients with increasing autonomy living lives by their own priorities, in partnership and consultation with physicians as needed. To achieve medicine's new potential, it must be optimized around the wants and priorities of the ultimate stakeholder —the party that has the most at stake in how it all plays out: the patient. Patient design is the approach that can make it happen. ### **DOI** – https://doi.org/10.2196/39178 Full-text - https://www.jmir.org/2022/8/e39178 Free Altmetric Report – https://jmir.altmetric.com/details/135218830 Keywords - Patient, patient design, user design, patient centric, patient focus, digital health, Future, Empowerment, Involvement, Participatory, Engagement, Participation, patient centered, patient centered JMIR Publications is a leading, born-digital, open access publisher of 30+ academic journals and other innovative scientific communication products that focus on the intersection of health and technology. Its flagship journal, the Journal of Medical Internet Research, is the leading digital health journal globally in content breadth and visibility, and it is the largest journal in the medical informatics field. To learn more about JMIR Publications, please visit https://www.JMIRPublications.com or connect with us via: **YouTube** – https://www.youtube.com/c/JMIRPublications Facebook - https://www.facebook.com/JMedInternetRes Twitter - https://twitter.com/jmirpub **LinkedIn** – https://www.linkedin.com/company/jmir-publications Instagram - https://www.instagram.com/jmirpub/ Head Office – 130 Queens Quay East, Unit 1100 Toronto, ON, M5A 0P6 Canada Media Contact - Communications@JMIR.org The content of this communication is licensed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, published by JMIR Publications, is properly cited.

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