An independent review of research findings that support the benefits of Online Communities for Healthcare
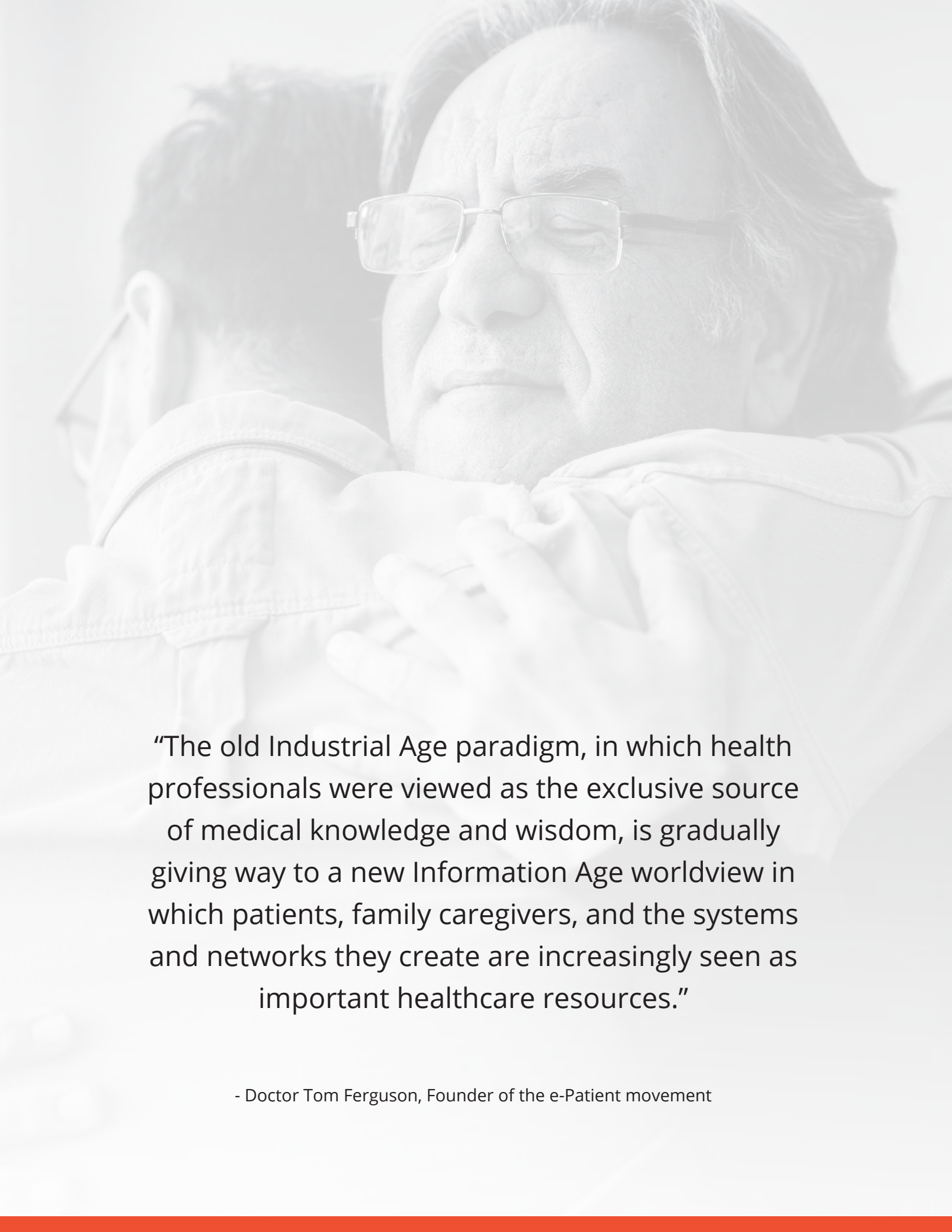
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"The old Industrial Age paradigm, in which health professionals were viewed as the exclusive source of medical knowledge and wisdom, is gradually giving way to a new Information Age worldview in which patients, family caregivers, and the systems and networks they create are increasingly seen as important healthcare resources."

- Doctor Tom Ferguson, Founder of the e-Patient movement

80%

of US citizens had previously gone online to look for information about a health topic.[1]

People who are activated about their health are more likely to be satisfied with treatments and report good outcomes.

Online peer support communities addressing health issues were one of the earliest uses of the Internet. They have continued to grow and evolve along with the internet and there is now a growing body of evidence that supports the many benefits of online communities for healthcare.

When people have a health problem, it is natural to look online to understand and explain it. In research from 2012, Pew Research found that 80% of US citizens had previously gone online to look for information about a health topic.[1] Google Health Chief David Feinberg said that in 2019 about 7% of Google searches were health related.[2] To provide perspective, this equates to about 70,000 searches a minute or a billion health inquiries a day. A 2017 study found that 43% of people looking for health information online went first to a trusted source rather than simply running a wide-open search.[3]

People looked for more than information, however. Many people also looked online to connect with others like them, with people struggling with similar health conditions and symptoms. That search for people to connect with has several dimensions: 1) to find stories about other people's experiences, treatments and coping mechanisms, 2) to obtain support from others who really understand their world, and 3) to exchange knowledge ranging from effective treatments to best doctors.

In 2010, Pew Research found that one in four people with a chronic condition went online to find others with similar issues.[4] It is likely that the number has increased rather than decreased in the 9 years since that study, although formal research is sparse.

Research from 2018 on teens and young adults reinforced earlier findings, noting that:

- Two in five young people between 14 and 22 years old have gone online looking for peers with health conditions like theirs.

- A full 84% of those teens and young adults looking for peers found someone.

- Of those who found peer support online for a health condition, 91% say their last experience with an online peer was somewhat or very helpful.[5]

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7%

of Google searches are health related.[2] To provide perspective, this equates to about **70,000** searches a minute or a **billion** health inquiries a day.

A recent WEGO Health study found that 91% of users who are part of a patient community said that the community impacted their health decisions.[6]

A meta study from 2016 also found that online peer interactions about health conditions positively impact how individuals self-manage their conditions. The study also found that the social support provided in online groups meets a need that is hard to address offline.[7]

These studies, along with anecdotal evidence, say that there is significant hunger for information, support and encouragement from peers about health issues.

Benefits

Studies have shown a wide range of benefits from online communities. **Key areas where benefits have been documented include:**

- Feeling supported
- Finding information
- Maintaining relationships with others
- Affecting behavioral choices
- Experiencing health services
- Learning to tell their story
- Visualizing disease
- Increasing health literacy[8]

Some studies show that peer support (not necessarily online) can be more effective than expert support in helping people make health behavior changes.[9][10] Studies point to peer support as increasing success in quitting smoking and consuming less alcohol as well as managing conditions ranging from diabetes to mental health. Peer support has been shown to help families and babies in NICUs with impacts ranging from confidence building to shorter NICU stays.[11]

Patients who participate in peer support have higher levels of quality of life and more positive attitudes about coping with illness. Peer support and group practice has also been shown

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1 in 4

people with a chronic condition went online to find others with similar issues.[4]

Studies have shown peer support has a significant positive impact on the health system.[16]

to increase adherence to mindfulness meditation as a stress reduction tool in a call center environment.[12] A 2019 study looked at changes in Patient Activation Measure (PAM) scores based on participation in an online community. Although they only followed users for 3 months, they found subtle increases in PAM scores, with the greatest amount of change occurring among the least-activated patients.[13]

Peer support has also been shown to be helpful for individuals dealing with mental illness. Specific benefits cited include, "greater social connectedness, feelings of group belonging and by sharing personal stories and strategies for coping with day-to-day challenges of living with a mental illness."[14] Finally, there are intangible benefits for participants including increasing their knowledge and health literacy as well as learning how to tell their stories for impact.

Participants in online peer support groups report that they value hearing first-person stories and being able to connect with peers.

Both active participants and "lurkers" have been found to experience positive outcomes from communities. Most online health communities develop "superusers," who post frequently, actively support others in the community, and are knowledgeable about the disease or condition. Superusers or peer moderators play a key role in helping online communities grow and flourish.

How online communities can support the health system

A study published in the New England Journal of Medicine found that 10 superusers can sustain a health community of up to 1000 members.[15] The study highlights the way that online health communities – and the superusers who sustain them – can support strained health systems. Managed appropriately, superusers can amplify health system messages and provide both emotional and factual support for both acutely and chronically-ill individuals.

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To achieve these benefits, however, health systems need to support online health communities. **Key recommendations for how to do this include:**

- Support the growth and integration of patient-driven online health communities
- Recognize and support superusers
- Develop robust evaluation systems for superusers

The Peers for Progress center at the University of Chapel Hill, North Carolina, tracks global examples of peer support and outcomes achieved. Though their focus is more on peer educators and lay workers than online support groups, the host of studies they track demonstrate the significant positive impact of peers on the health system.[16]

Organizations may be wary of sponsoring and supporting online health systems out of a fear that they will provide a forum for users to band together to complain or challenge treatments. Research has shown, however, that people who are activated about their health are more likely to be satisfied with treatments and report good outcomes than those who are at lower activation levels. Any such issues that arise can be appropriately managed by site policies and skilled site moderators, who can help get the issue resolved, correct misperceptions, and direct users to appropriate offline resources.

Mayo Clinic Connect is a great example of a successful sponsored health community. Its 80,000+ users are supported by a community manager, 5 half-time staff members and multiple community mentors or champions. Mayo Clinic recognizes the benefits of peers guiding peers and of the increase in appointments at Mayo Clinic from community participants.

Online health communities can advocate for new treatments and participate in innovation by addressing ideas and concepts that the traditional medical community has been slow to adopt.

Some examples of communities that play this role include:

- Movements to foster and push for "patient-directed research."[17] This has happened in areas such as Parkinson's Disease and HIV/AIDs research.

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Only 10 out of 4,600

posts in an online breast cancer community were inaccurate or misleading.[21]

The vast majority of health communities promote reliable and trustworthy information.

- Patient communities that form collaboratories and share new insights, disrupting medical hierarchies.[18] Examples of these include communities like #openaps and #nightscout that have disrupted traditional approaches to diabetes treatment. Their work has resulted in several examples of patient-created artificial pancreases, which has changed the science of diabetes management.[19] At least partly as a result of their work, the FDA and device community have expedited the work of in creating an artificial pancreas.

Rather than fearing these impacts, health systems can use patient communities as a part of internal change and innovation initiatives.

Information Accuracy

You may wonder, however, how reliable peers are as a source of information for individuals with health conditions. The online spread of other dubious health information, headlined by anti-vaccination groups, has made many people skeptical about online peer support. It appears, however, that the vast majority of health communities promote reliable and trustworthy information.

A 2016 study rated health information exchanged in 25 threads across several sites. Their ratings found that the information exchanged was likely to be of reasonably high quality by a factor of 4 to 1. Even when the information was of lesser quality, it was unlikely to lead a reader to act inappropriately.[20] This is in line with several earlier studies. A 2006 study showed that only 10 out of 4,600 posts in an online breast cancer community were inaccurate or misleading. Of those 10 misleading posts, 7 were found and corrected within an average of 4½ hours.[21] A 2009 study found that information posted in an online diabetes forum closely aligned with clinical guidelines.[22]

Although there is evidence that reputable communities can self-police the quality of resources and information posted, there's also a case for educating community moderators – and the general public – about how to spot and address any misinformation, rumors, quackery and falsehoods. Moderators and peer experts can help keep a community's knowledge on track, as highlighted in a 2019 study that analyzed their impact.[23]

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By sponsoring online peer-to-peer support communities, health systems, payers, and employers can improve the health of the populations they serve.

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Conclusion

There is good reason to invest in online communities to help individuals support one another. Peer support communities are a powerful tool to support individuals in dealing with illness, making health behavior changes, and addressing stress and mental health concerns. Research highlights the role online communities can play in increasing self-efficacy, reducing the stress of illness, and improving health outcomes.

Peer support communities tap into some of our best instincts for building understanding through associating with others who have shared experiences. By sponsoring online peer-to-peer support communities, health systems, payers, and employers can improve the health of the populations they serve and build the resilience of their communities. The best way to understand and explore benefits is by sponsoring a community to see these benefits in action.

About Jan Oldenburg

Jan Oldenburg, FHIMSS, is the principal in Participatory Health Consulting. She advises and mentors startups and healthcare organizations about the evolving digital health landscape. Ms. Oldenburg has focused on digital transformation in healthcare for 20 years. Her experience includes leadership roles in several advisory firms, most recently EY. She has also served as the Vice President of Patient and Physician Engagement in Aetna's ACO organization and held several senior leadership roles in Kaiser Permanente's Digital Services Group and at HealthPartners.

She is the principal editor of both *Participatory Healthcare: A Person-Centered Approach to Transforming Healthcare*, published in *2016 and Engage! Transforming Healthcare Through Digital Patient Engagement*, published in 2013. Ms Oldenburg also authored chapters in the Third Edition of *Medical Informatics and The Journey Never Ends*. She's the former co-chair of the HIMSS Connected Health Committee and sits on the board of the Society for Participatory Medicine.

Jan brings her experience to Synergiq Solutions as a Patient Engagement Consultant. To discuss the findings of this research, contact Jan through her website.

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About Synergiq Solutions

We're driven to make a positive difference – for the individuals, families and informal caregivers who benefit from belonging to our online health communities, and for the organizations we work with. We apply our community capabilities – strategy, creativity, communications and technology – to engage members in experiences where knowledge is shared, collaboration happens and meaningful relationships develop. The end result? Better health outcomes.

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