

Supporting Intellectual Contributions from Online Health Communities

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The current approach of relying primarily on institutional experts to create knowledge to solve humanity's problems is insufficient to meet the scale, diversity, and novelty of people's needs. Clinical work and clinical research are two domains where reliance on experts—while necessary—is also a key bottleneck. There aren't enough doctors for most people around the world [4]. Research done in academic and industry labs uses sophisticated tools barely accessible to most people.

Increasingly, easily accessible informational and physical resources have *somewhat* bridged the gap between patients' needs and their skills. Patients and caregivers inform themselves via internet based resources, build their own tools, and participate in experiments [1]. Dissatisfied or marginalized by existing processes and outcomes, many patient communities—including chronic conditions and rare disorders—stand to gain a lot from such collaborative efforts [2, 3]. Online health communities provide the foundation for such *uninstitutionalized* conversations, brainstorming, and implementation. However, success is uneven. While communities with clear leaders, organizational roles, and technical expertise have flourished, many others have not.

My research with online communities suggests that there's a massive opportunity to accelerate knowledge creation using granular data acquisition tools and online learning platforms . In this abstract, I summarize design and evaluation of tools that highlight two ways to realize this vision. First, Hevelius is a motor impairment assessment tool for patients to conduct neurological assessments online. A rare disease community has provided fine-granular data and insights from their homes that current in-clinic assessments fail to capture [in submission]. Second, Gut Instinct is a social computing system that supports procedural knowledge acquisition for experimentation. A fermentation community used Gut Instinct to successfully design and run between-subjects experiments to test their intuitions [5]. These results suggest exploring ways of producing knowledge that are distinct from the dominant model of institutionally-situated experts testing their ideas on subjects in a lab or a clinic. More constructively, these systems demonstrate how knowledgeable and committed people can be aided and amplified by technology in creating scientific knowledge.

References

- [1] Francesco Fornai, Patrizia Longone, Luisa Cafaro, Olga Kastsuichenka, Michela Ferrucci, Maria Laura Manca, Gloria Lazzeri, Alida Spalloni, Natascia Bellio, Paola Lenzi, et al. Lithium delays progression of amyotrophic lateral sclerosis. *Proceedings of the National Academy of Sciences*, 105(6):2052–2057, 2008.
- [2] Maia Jacobs, Galina Gheihman, Krzysztof Z Gajos, and Anoopum S Gupta. " i think we know more than our doctors" how primary caregivers manage care teams with limited disease-related expertise. *Proceedings of the ACM on Human-Computer Interaction*, 3(CSCW):1–22, 2019.
- [3] Haley MacLeod, Kim Oakes, Danika Geisler, Kay Connelly, and Katie Siek. Rare world: Towards technology for rare diseases. In *Proceedings of the 33rd Annual ACM Conference on human factors in computing systems*, pages 1145–1154, 2015.
- [4] World Health Organization. Dangers of poor quality health care revealed ‘in all countries’: WHO report. <https://news.un.org/en/story/2018/07/1013942>, 2008. [Online; accessed 19-July-2008].
- [5] Vineet Pandey, Tushar Koul, Chen Yang, Daniel McDonald, Mad Price Ball, Bastian Greshake Tzovaras, Rob Knight, and Scott Klemmer. Galileo: Citizen-led experimentation using a social computing system. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, pages 1–14, 2021.