Challenging Our Ideas of "Community" – A Case Study

A Summary and Reflection on "The Pain Was Unbearable. So Why Did Doctors Turn Her Away?" from Wired.

Below is a summary of an article by writer Maia Szalavitz that describes a case of group harm resulting from repository research. Ms. Szalavitz's article provides a real world example that may help you broaden your understanding of "community" and potential pathways to harm in repository research. The full article, "The Pain Was Unbearable. So Why Did Doctors Turn Her Away?", is available on Wired.com.[1]

Ms. Szalavitz tells the story of Kathryn, a woman living with severe endometriosis. Endometriosis is a condition where tissue similar to the lining of the uterus grows *outside* the uterus. This can cause intense pain.[2][https://my.clevelandclinic.org/health/diseases/10857-endometriosis] For many years, Kathryn took opioid medication prescribed by her doctor to manage her pain. When her symptoms returned, she went back to the hospital expecting care.

After several days of care, Kathryn was told she would no longer receive opioid medication to manage her pain. Nothing about her condition had changed, and no one explained why she would not receive care.

Soon after, Kathryn received a letter from her doctor ending their relationship. The letter mentioned NarxCare, a program that uses patient data to look for "drug-seeking" behavior. Kathryn went online to learn more and found many people with chronic pain who had the same issue. On social media and in online forums, they shared their experiences and tried to understand why the system had flagged them.

From these discussions, Kathryn figured out what probably caused her doctors to withhold her needed pain medication. She had adopted two older dogs who needed pain medicine, too. Since animal prescriptions are listed under the owner's name, NarxCare thought she was misusing opioid medication.

This story shows how repository-enabled technology can unintentionally harm communities. Researchers and oversight committees learn about examples where communities have experienced harm from research before. But big health data research can also create new social dynamics, new risks, and even new kinds of communities.

As we enter a new era of massive repository-enabled research and open-hypothesis research, we need to be careful about how this research might impact communities, both established and new.

Sources and Further Reading

1. The Pain Was Unbearable. So Why Did Doctors Turn Her Away? | WIRED. Accessed November 7, 2025.
    https://www.wired.com/story/opioid-drug-addiction-algorithm-chronic-pain/

2. What Is Endometriosis? Cleveland Clinic. Accessed December 4, 2025.
    https://my.clevelandclinic.org/health/diseases/10857-endometriosis