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OVERVIEW

Social media based digital health communities (DHCs) play a significant and poorly understood role in shaping the health experiences of numerous patients and caretakers.

To better understand the impacts of DHCs on patient health, this project profiled a small cross section of Facebook groups. We published our findings on [The DHC Observer](#). A summary of our findings is presented here.

STATUS QUO

An estimated 80,000 English language Facebook groups focus on health topics. The groups range in size from three members to over 2.2 million. They include some of the oldest, most active, and most established groups on Facebook.

Despite the prevalence and importance of these groups, physicians, journalists and academics appear to be mostly uninterested. With just [one exception](#), the *New York Times* and *Washington Post* have not covered them. A PubMed search for the patient benefits of Facebook groups returns three relevant articles. None mention the kinds of significant benefits we've identified and documented in our initial survey.

EXAMPLE FACEBOOK GROUPS AND THEIR HEALTH BENEFITS

Autism: autistic adults advise parents and battle 'cure autism' therapies.

NICU parents: parents of children born prematurely pool advice on navigating parenthood.

Adrenal disease: patients popularize emergency kits underprescribed by doctors.

Celiac disease: patients swap recipes, info in a fast growing new group.

ALS: members maintain a database of global ALS clinical trials.

SLC6A1 gene: parents document one child's life with an orphan disease so rare it doesn't yet have a name.



Photo of Charlie Fry, who was diagnosed with SLC6A1 in August 2019.

IBD: afflicted individuals can share the messy details of their condition... even from the toilet.

Orphan disease: since 2007, patients share info and convene conferences about their 3 in 1,000,000 disease.

Asthma: members take responsibility for upholding community standards.

Spinal Muscular Atrophy (SMA): the group raised >\$1 million CAD in just 4 months for child suffering from SMA.

Prostate Cancer: men raise awareness of lower risk strategies versus surgery and irradiation.

Aussies: a group focuses on issues relating to Kawasaki Disease that are unique to Australia.

TBI: members share stories plus strategies for managing traumatic brain injury.



Read all of the articles and our findings at <https://digitalhealthcommunities.org>