

**Social support models and engagement patterns of Online Health Communities
A systematic scoping review**

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Sheffield Hallam University's *Lab4Living* presents

Design4Health2024

International Conference

equilibrium

in a time of

permacrisis

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Editors: Claire Craig, Paul Chamberlain

With thanks to Helen Fisher and Cassie Khoo

Proceedings of the 7th International Conference on Design4Health

Sheffield, United Kingdom, 25th-27th June 2024

Lab4Living, Sheffield Hallam University

Welcome to the 7th International Design4Health Conference.

We continue to live in a time of unprecedented change. Since Design4Health2018, we have experienced a global pandemic, been confronted by economic uncertainty, witnessed climate change's devastating impact, and continue to experience societal inequality. Advances in AI and other technologies, whilst promising new opportunities, also raise ethical challenges.

It seemed only fitting that this was reflected in the overarching theme of our 2024 conference – hence our title: **equilibrium in a time of permacrisis**.

The term Permacrisis describes an extended period of instability. We thought it reflected well recent events and the global challenges we continue to face. We also felt it important to recognise that history has shown how new ways of thinking can be borne during periods of instability and insecurity. This book of abstracts reflects the richness and breadth of research that is occurring in responding to these global challenges and the uncertainty they bring.

Authors have responded in different ways to the theme and in the way they have chosen to write and present their abstracts reflects a diversity of styles and approaches. We are excited to hear more over the coming days as work is presented and shared.

Above all we hope the 2024 conference will offer space to pause, reflect and examine how design research and creative practice might enable us to envision alternative futures as we move forward to consider a new equilibrium.

Thank you

Conferences are borne out of huge amounts of work that happen behind the scenes and this year's conference is no different. Kirsty Christer who had been so instrumental in organising previous conferences has passed the baton on to Julie Roe who has worked tirelessly over the last few months in the planning of the conference.

Special thanks to Nick Dulake, Ursula Ankeny and Helen Fisher for all their work in pulling everything together and to the wider Lab4Living team.

We are also indebted to our conference organising committee who have been with us from the start of this process. Thanks to:

Kirsty Christer – Conference Co-ordinator, Lab4Living
Nick Dulake – Lab4Living
Cassie Khoo – Good Health Design, AUT, New Zealand
Kaisu Koski – Lab4Living
Joe Langley – Lab4Living
Chris Lim – University of Dundee
Ivana Nakarada-Kordic – Good Health Design, AUT, New Zealand
Graham Nesbitt – Lab4Living
Steve Reay – Good Health Design, AUT, New Zealand
Heath Reed – Lab4Living
Julie Roe – Lab4Living
Noémie Soula – Lab4Living
Michael Tan – Lab4Living

Thank you to our sponsors Lightmain and Research England.

Thank you to all our reviewers on our scientific committee for their support in reading and commenting on the huge volume of abstracts we received.

Aaron Davis	Kaisu Koski	Caylee Raber
Bill Noble	Kirsty Christer	Chris Lim
Daniel Masterson	Kate Sellen	Sarah Munce
Erna Snelgrove-Clarke	Michael Tan	Sarah Walker
Gillian Harvey	Marika Grasso	Smizz
Helen Fisher	Marney Walker	Stephen Reay
Ian Gwilt	Nick Dulake	Ursula Ankeny
Ivana Nakarada-Kordic	Noemie Soula	Virginia Dickson-Swift
Joe Langley	Nadia Beyzaei	
Juliana Privitera	Nicola Kayes	

And finally thank-you for being willing to share your work, to enter into conversation and discussion, for your energy and passion in advancing the role of design and creative practice in the promotion of health and wellbeing. We hope you enjoy the conference.

Warmest wishes,
Professor Claire Craig and Professor Paul Chamberlain,
Lab4Living, Sheffield. UK

90. Social support models and engagement patterns of Online Health Communities: a systematic scoping review

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Themes

Technologies in health, Contexts of care, Other

Keywords

Online Health Community, Scoping Review, Social Support model, Community engagement, Peer-expert

Submission type

Paper presentation

Abstract

Background

Coping with a health condition is an ongoing process that demands continuous self-care and social support. People increasingly engage in online health communities (OHCs) to share their health experiences (Sanger et al., 2023; Wang, Zhao, and Street, 2017).

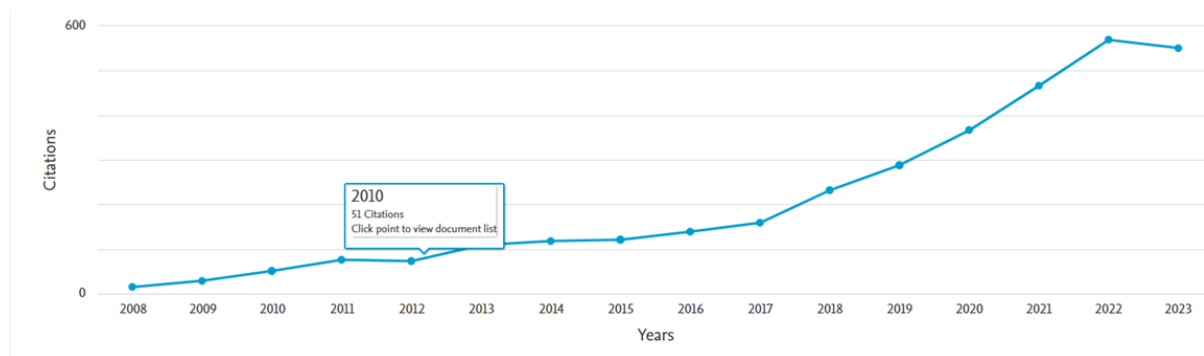


Figure 1. Overview of citations of relevant OHC studies (Source: Scopus analytics).

Research has kept pace with an accumulation of OHC studies (see figure 1). Although, a clear and systematic understanding on the social support involved is lacking. This study examines OHCs through a systematic scoping review in the field of design and health informatics. By analysing and charting existing research over the course of fifteen years, we were able to identify community engagement patterns and social support models. Hence, this paper contributes with principal knowledge on the design of social structures of OHCs and discusses novel implications for understanding social support in OHCs.

Objective

In order to extend the body of knowledge on OHCs at the interplay of design and health informatics, this research aims to create a systematic understanding of community engagement and social support structures in OHCs. Our research is guided by the following research question: What is known from the existing literature about the nature and social support of OHCs for people coping with a health condition?

Method

Drawing on Hilary Arksey & Lisa O'Malley (2005) we employed a systematic scoping review method consisting of five steps. After *Step 1: identifying the research question* (see above) we continued to set up the sample for the review by *Step 2: identifying relevant studies*. For this, the search term “Online Health Community” led to an initial list of studies which we limited to the field of interest, by including the top tier journals and conference papers: British Medical Journal, Journal (BMJ) of Medical Internet Research (JMIR), Design for Health (DfH), Design Science, She Ji, BMC Health services and ACM conference proceedings. We excluded the review papers and filtered out the ‘mathematics’ listed topic, leading to a list of 130 relevant papers. A more fine-grained sample analysis in *Step 3: study selection*, led to the final sample of papers. The period 2005 – 2023 was chosen as a first selection criterion in order to include the first top cited article published in 2005 (Maloney-Krichmar and Preece, 2005), next to including the most recent OHC development over the last three years. Second, only those papers with OHC in the keywords or title were included. Third, papers with less than ten citations before 2020 were excluded. This narrowed down the final sample to 99 papers. Characterized in figure 2 by origin, 10 countries are represented by the reviewed studies.

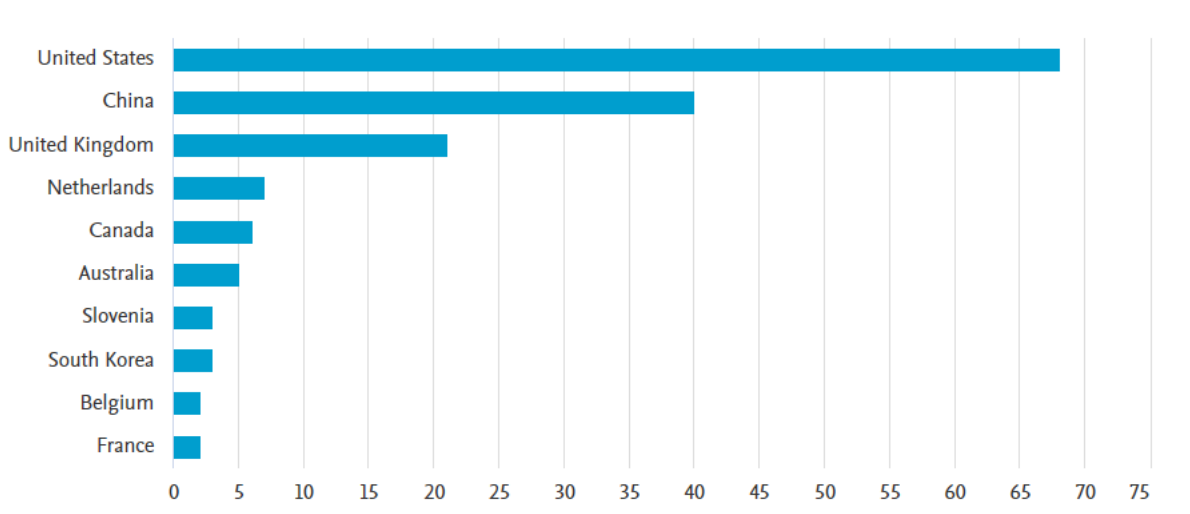


Figure 2. Sample of OHC studies by country (Source: Scopus analytics).

For *Step 4: charting the data* we analysed the abstracts and crafted the coding scheme in atlas ti. The codes were clustered and categorized. Next we iterated and refined this coding scheme in such a way that social engagements in OHCs were classified into distinctive categories. We undertook this manually using tabulation charts in Excel as visual aids. *Step 5: collating, summarizing and reporting the results*. Having charted the social support categories, we were able to summarize the number of OHC studies. By this systematic reporting of the data, we were also able to determine patterns of commonalities and differences, make comparisons across OHC studies and identify contradictory evidence regarding specific engagements.

Results

Two social support models

From the total number of relevant studies concerning OHCs (n=99) two models of social support are distinguished: a peer-expert model found in the largest cluster of studies (n=34) and the care professionals' model (n=29).

Table 1. Charted social support models (Source: Authors own)

Social support model		n=63		
Peer-expert model		n=34	Care professional model	n=29
○ Sharing Experience and feelings	8	○ Aids to in-person care	8	
○ Peer to peer support	16	○ Online coordination, communication, consultation services with CP	16	
○ Peer expert recommendations	10	○ Physician recommendations	5	

The peer-expert model facilitates sharing experiences (n=8), seeking and providing peer-to-peer support (n=16) and peer recommendations (n=10) exemplified in for instance the Patients-like-me community (Wicks et al., 2010; Frost and Massagli, 2008). The care professional model was mostly studied in facilitating an additional aid to in-person care (n=8), by online coordination, communication and consultation services with nurses and physicians (n = 16) and providing physician recommendations (n=5).

Community engagement patterns

In characterizing the nature of social engagements in OHCs, four clusters of social engagement were identified: *Information seeking and providing* is the second largest cluster of studies (n=31). *Compassion seeking and providing* cluster studies (n=24) social support ranging from empathic, emotional to spiritual support in which community members identify with others and experience connection. Within this category one study calls attention for negative emotion spread in OHCs. *Handhold for self-care* is a distinct form of social support found in 22 studies that related OHCs to self-management (n=9), health literacy (n=3), and empowerment including self-efficacy (n=10). *Social Safeguarding* concerns a cluster of studies (n=9) on community moderation, trust and privacy safeguarding.

Table 2. Charted community engagement patterns (Source: Authors own).

Community engagement patterns	n=86		
Information seeking and providing	n=31	Compassion seeking and providing	n=24
o Information seeking	26	o Social Compassion	13
o Information providing	5	o Empatic support / identify with others	3
		o Emotional support seeking	5
		o Spiritual support	2
		o Negative emotion spread in OHC	1
Handhold for self-care	n=22	Social safeguarding	n=9
o Self management, self therapy	9	o Community moderation	4
o Health literacy	3	o Trust	3
o Empowerment, self efficacy	10	o Privacy	2

Discussion

Principal findings

The two social support models (peer-expert and care-professional model) and the engagement patterns of seeking and providing a handhold for self-care and social safeguarding concern novel implication for the design of OHC structures and associated social support.

Comparison with prior work

The OHC research from a social support perspective is mainly focused on engagement patterns of information and compassion (ea. Wang et al., 2017; Gulati et al., 2012) that have been theorized in both social-psychology as well as health behaviour theories as a key strategy for people to cope with health problems (ea. Carver and Connor-Smith, 2010; Krause, 1986). This research adds two additional engagement patterns and models of the social structures.

Limitations

We acknowledge that unlike systematic reviews, the quantitative overviews typical for scoping reviews, do not appraise the quality of evidence from a smaller sample of studies. The publication bias of a tendency to publish positive results could have distorted the sample.

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