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# JOIN, STAY, OR GO?

## A Closer Look at Members' Life Cycles in Online Health Communities

Zheng Yao, Diyi Yang, John Levine, Carissa Low, Tenbroeck Smith, Haiyi Zhu, and Robert E. Kraut.

**This study combined behavioral log analysis, NLP-based content analysis, surveys, and interviews to examine temporal changes in members' participation in a cancer-oriented online health community.**

### Highlight findings:

- Most members left after their initial needs were met.
- For those who chose to stay, their motivations for participation shifted from receiving support to providing it to others in the community.
- Experienced members contributed the vast majority of content; their comments also contained more emotional support.
- However, experienced members also encountered challenges that threatened their commitment, including negative emotions related to other members' deaths.

# Intermittent health needs drive members to support groups




**Jacobs, Clawson & Mynatt (2016)**

But, what next?

# Research question


How do members' **motivation and behavior** change as they transition from newcomers to other roles or when they ultimately leave the community?






# Cancer Survivors Network

Home | About CSN | CSN Help | Contact CSN

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 Search CSN members

Discussion Boards

CSN Chatroom

CSN Email

Resources

About Me

Cancer.org

Welcome, zyao2

[Click here](#) to create or update your member "About Me" page

Members Online: 5







Log Out

CSN Home

Add to favorites | Manage your favorites

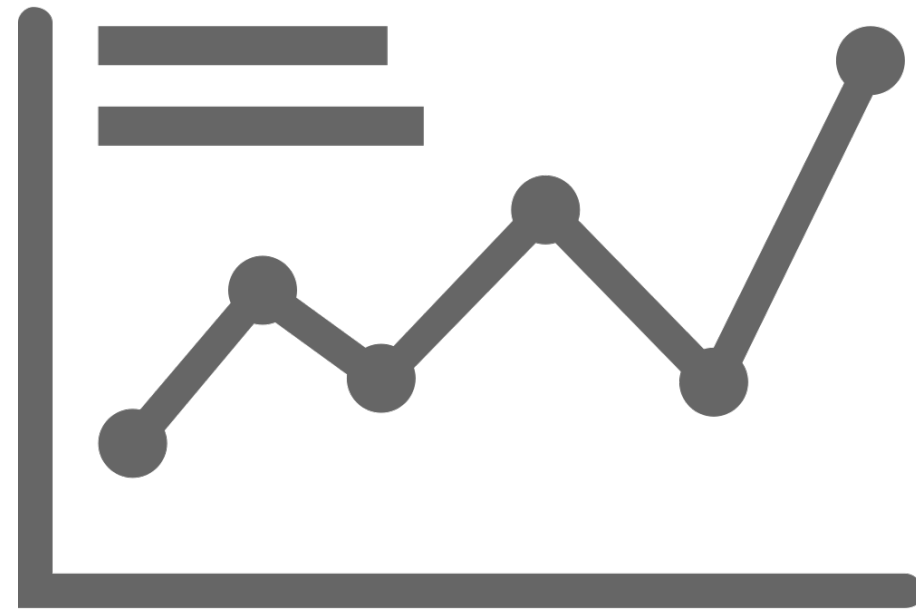
Discussion boards

Add new Forum topic

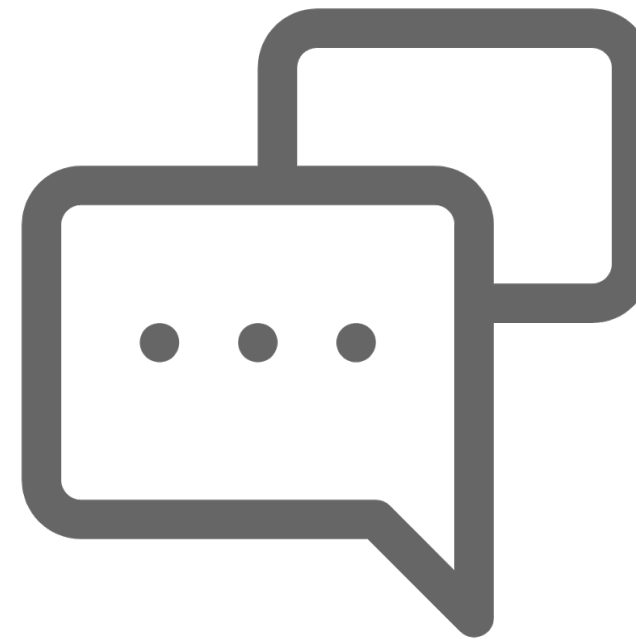
Forum	Topics	Posts	Last post
<b>Cancer specific</b>			
Please remember that these discussion boards are a public forum, which means open to the public (i.e. non-CSN members) and the content can be found via internet search engines. Members are strongly advised not to share personal identifiers such as real names, email address, telephone, street address, etc. can be used to identify you and link you to the content you provide. Other areas of CSN are restricted to members only and cannot be found by search engines.			
 Anal Cancer	2697 2 new	28738	Jan 31, 2021 - 10:20 pm By Fengshoe
 Bladder Cancer	402 1 new	1559	Feb 06, 2021 - 12:08 am By mikamouse
 Bone Cancers	291	1445	Feb 04, 2021 - 12:02 pm By Kat12
 Brain Cancer	1593	10930	Dec 31, 2020 - 1:28 am By arpithad
 Breast Cancer	27966 5 new	337424	Feb 03, 2021 - 9:25 am By ldp1957
 Childhood Cancer	...	...	Oct 27, 2020 - 8:41 pm

# Methods

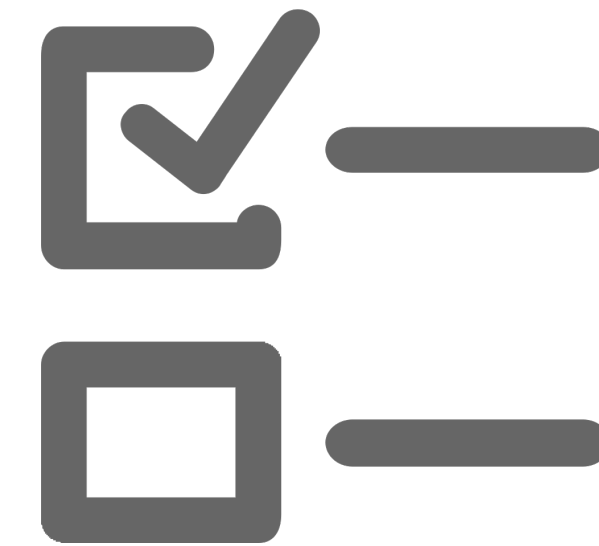
Usage Log Analysis  
+ Machine Learning



Interview

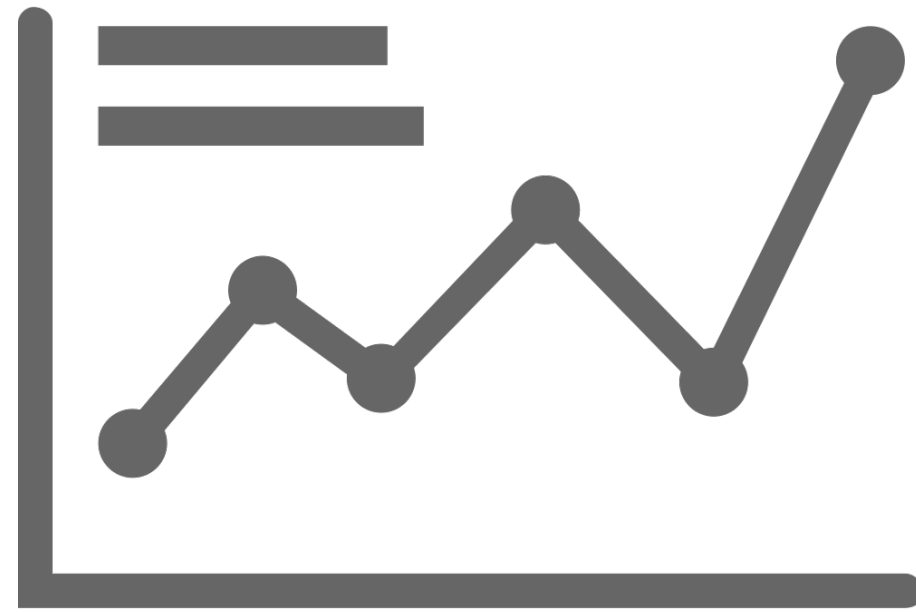


Survey



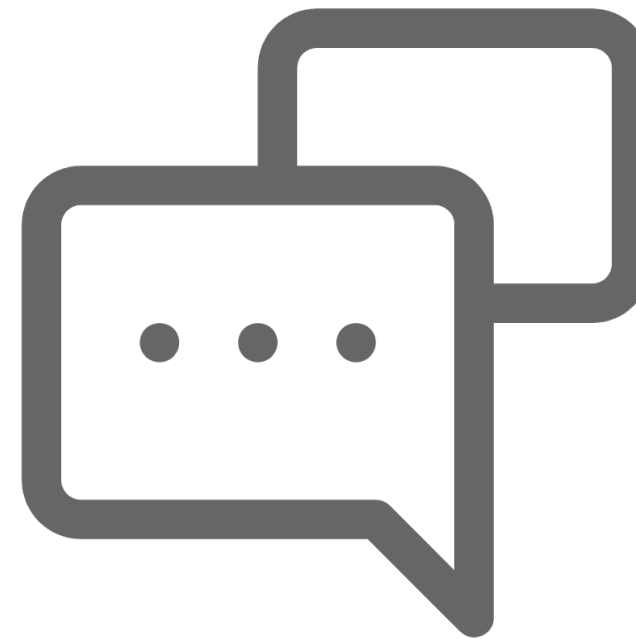
# Methods

Usage Log Analysis  
+ Machine Learning

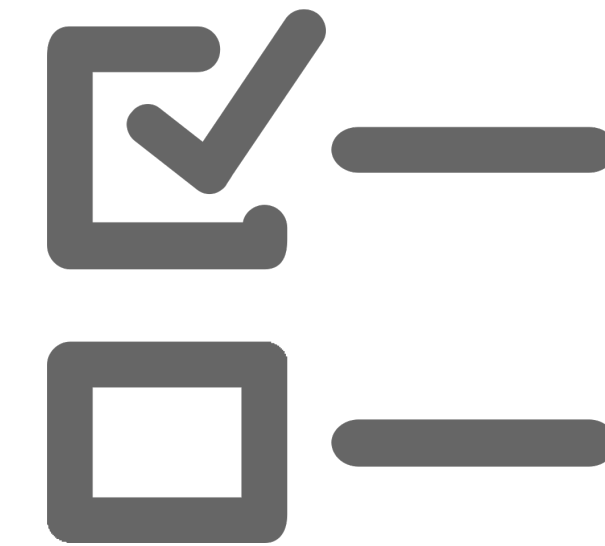


Behavior

Interview

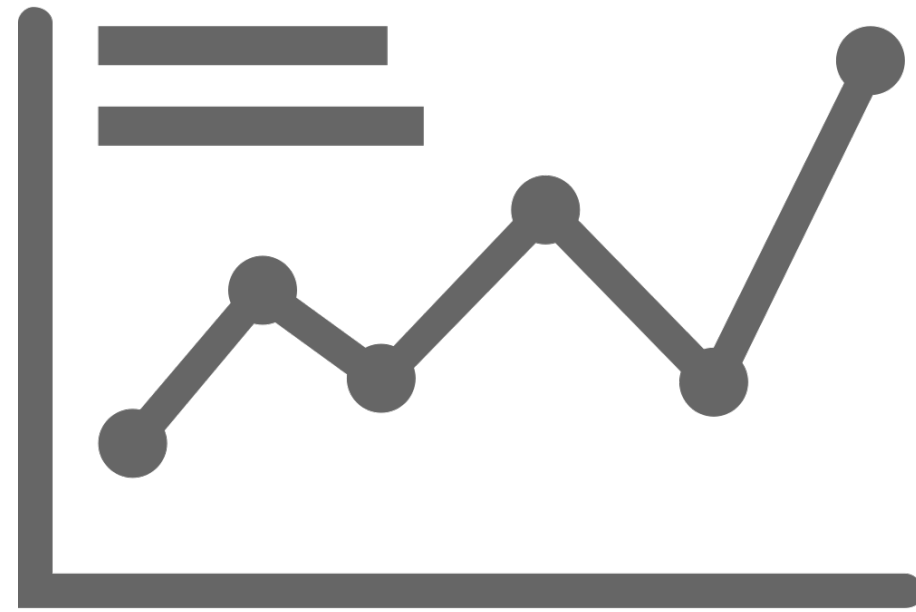


Survey



# Methods

Usage Log Analysis  
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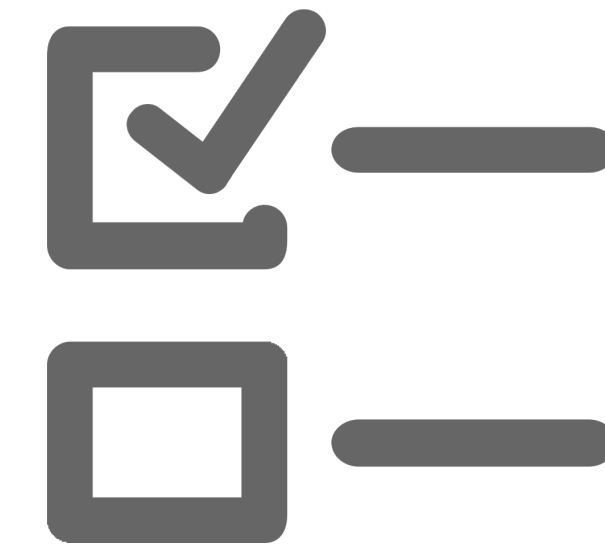


**Behavior**

Interview



Survey

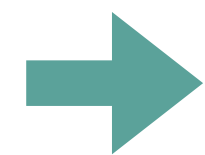


**Self-report**



# Members' Journey at health support groups

6,305,602 unique  
users visited CSN  
via Google search  
in a year

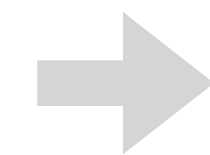


# Members' Journey at health support groups



# Members' Journey at health support groups

6,305,602 unique  
users visited CSN  
via Google search  
in 2017



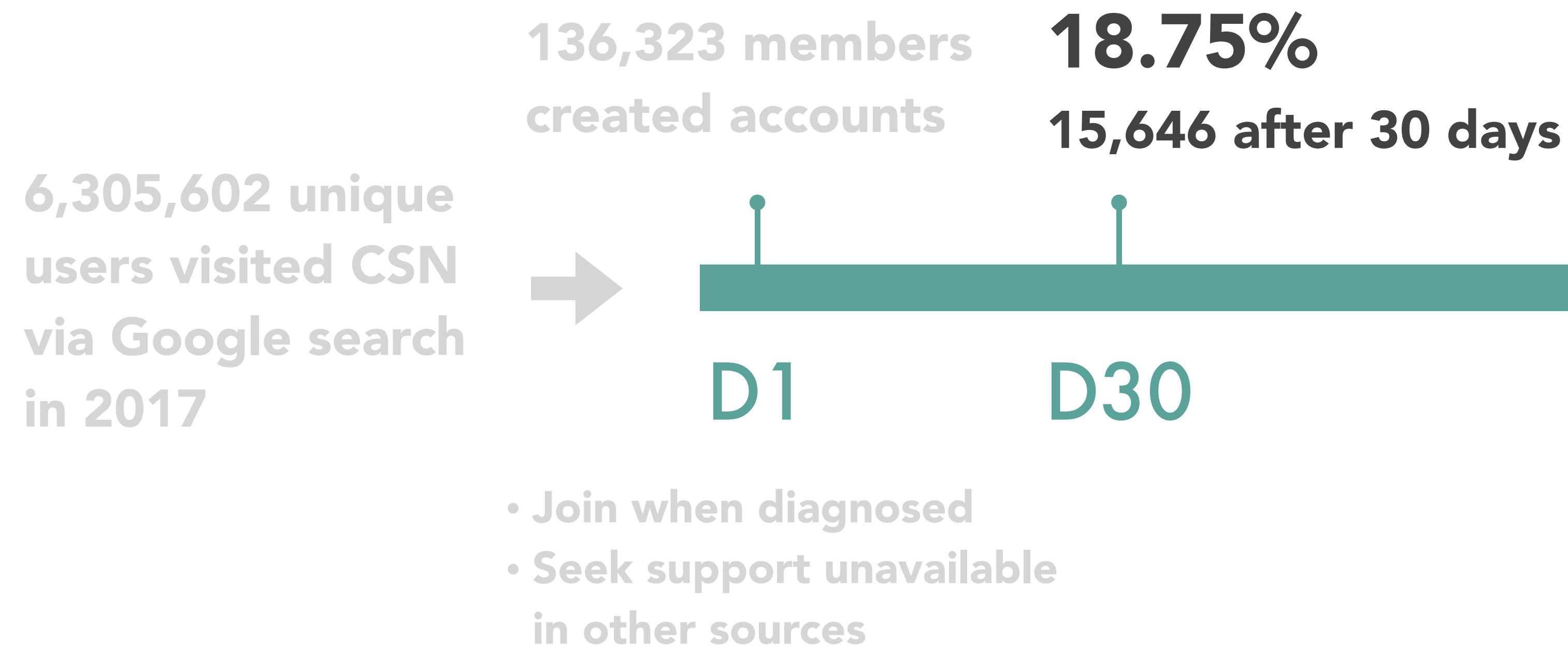
**136,323 members  
created accounts**



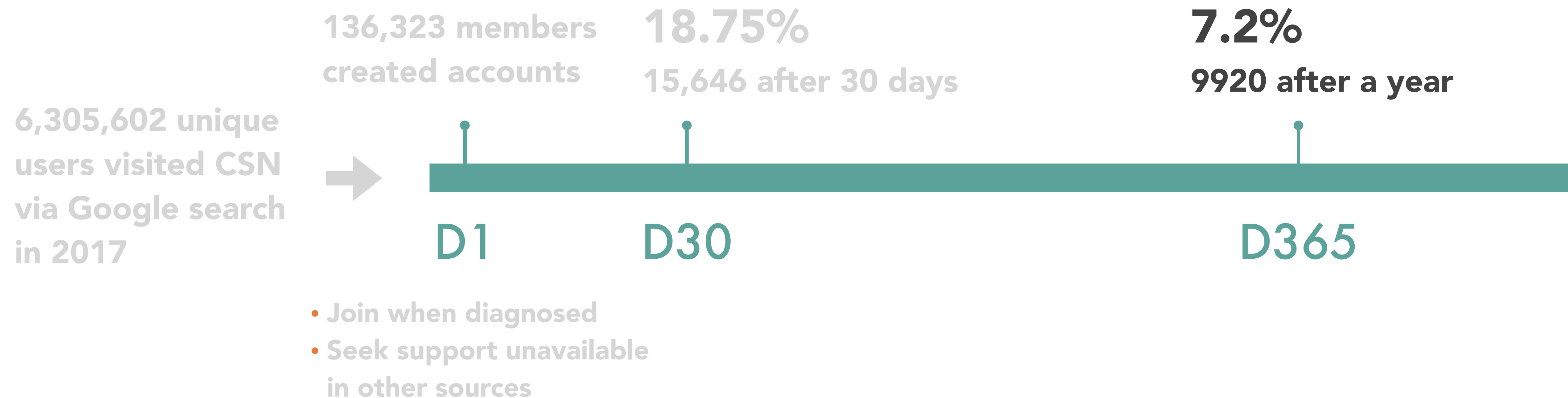
**D1**

- **Join when diagnosed**
- **Seek support unavailable  
in other sources**

# Members' Journey at health support groups

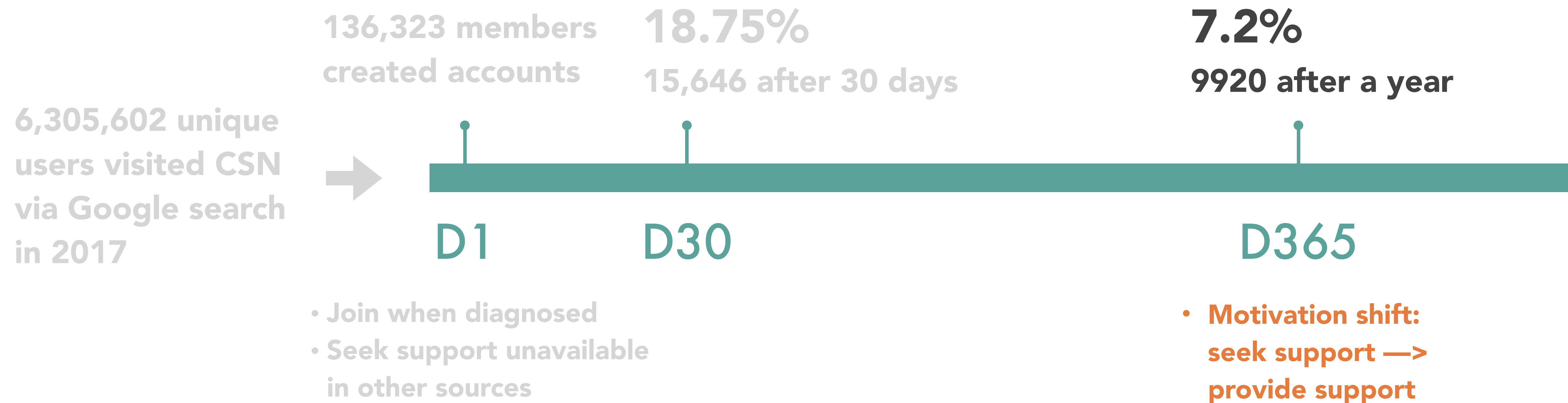


# Members' Journey at health support groups





# Members' Journey at health support groups



# Motivation shift - oldtimers want to pay back

Motivate  
to provide  
support ↑

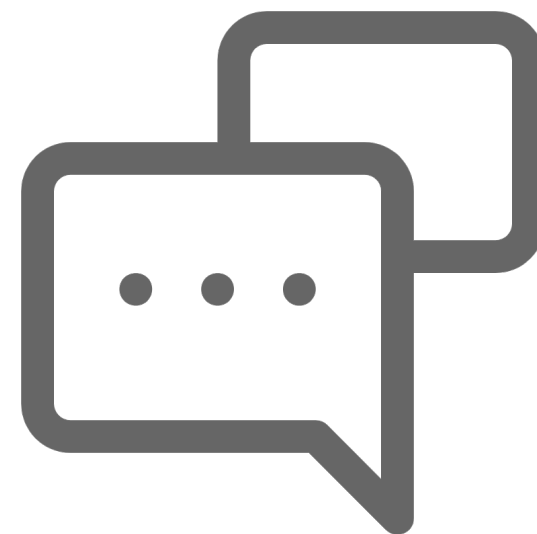


self-report

**P17:** [When I had chemo] there was one lady who had undergone chemo before and she was able to tell me, this is gonna hurt. She didn't lie. It hurt and she's able to describe it. That helped to take the fear of the unknown away. **And because of this type of thing, this type of support I've got, I wanted to give back."**

## Motivation shift - oldtimers care about their friends at CSN

**"Check in"**



P1: I know [these friends] at least on the cancer level. And I know where they go and what they do and what they like just through the forum and stuff.

**You know if I have time and I'm sitting around, I'll log in and just see who is online and then ask how's Ann, or how's Ted or how's Matt.**

**Similar stories shared by 6/20 interviewees**

## Motivation shift - oldtimers care about their friends at CSN

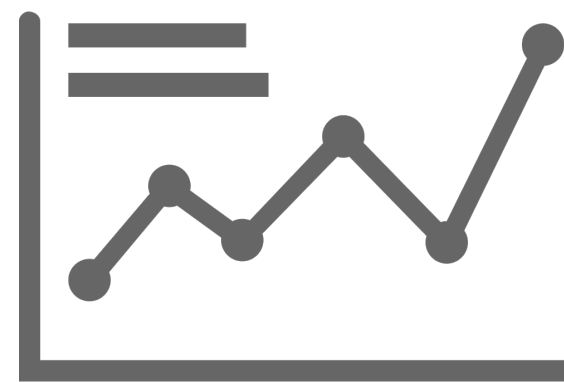
### Attachment ↑



Oldtimers' attachment to other CSN members was **positively** related with their tenure in the community. ( $p < 0.001$ ).

# Oldtimers provide more + higher quality support

Support  
provision ↑

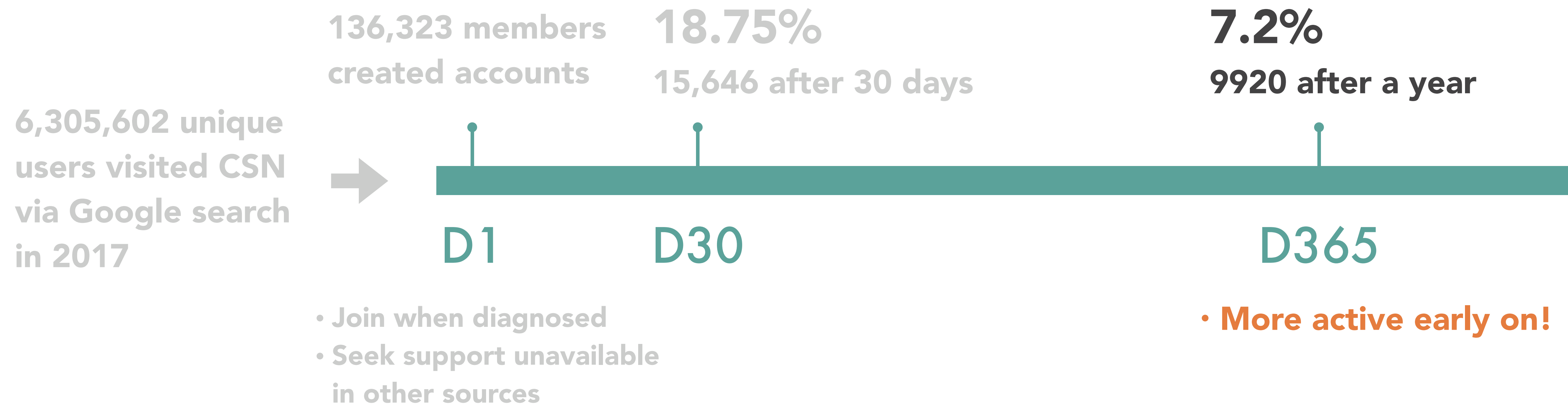


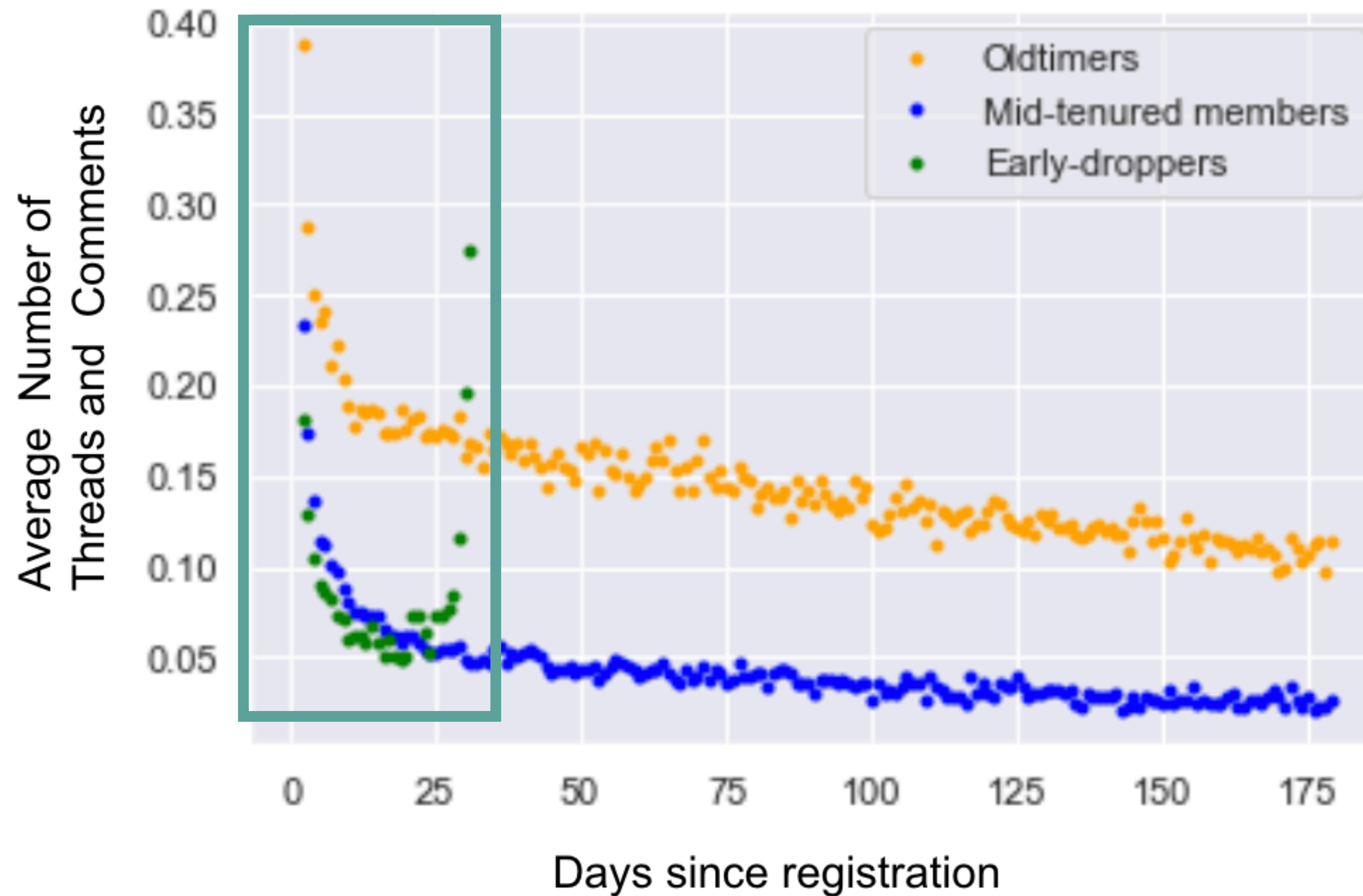
behavior

- Oldtimers contributed 85% comments at CSN.
- Oldtimers' comments contained significantly more emotional support than those of other members



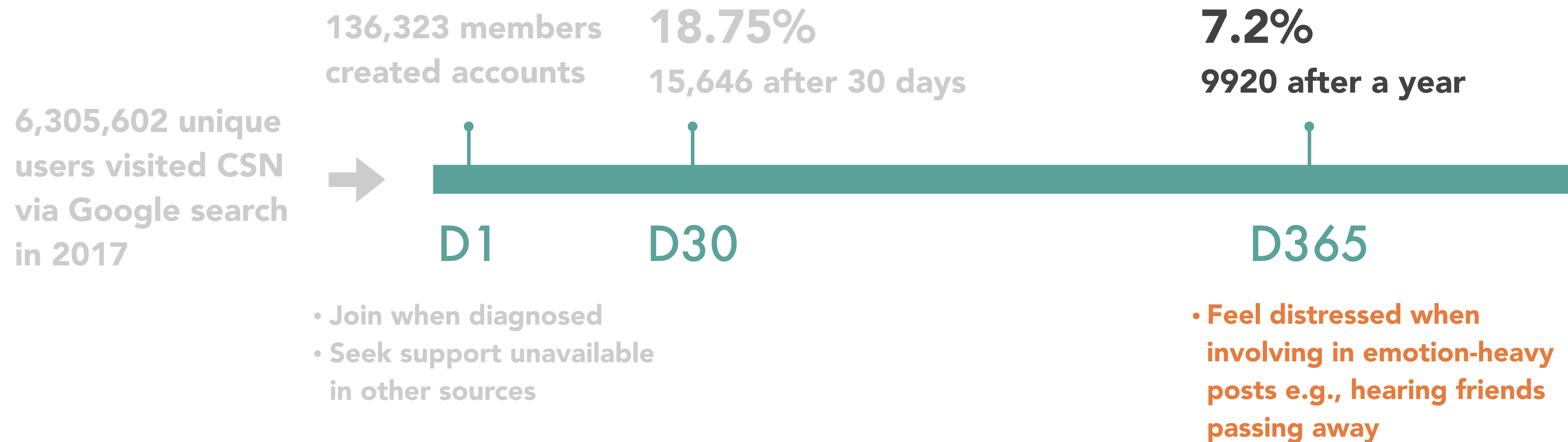
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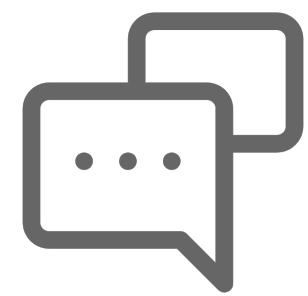


**Within the first 30 days, old-timers made more posts than non-old-timers**

## But, old-timers experience emotional struggle when participating



## Distress related to hearing fellow members' death



**P10:** I think probably a couple different things [for me to take a break]. Among them, when one or two of the women have died. **It really affects you because you you feel like you know some of these women via the posts on there...**



**P13:** It's got to be depressing after a while reading about people that lost their battle with cancer. **I could connect with them, though I never actually met them face to face, we had a bond because of a website.**

**Similar stories shared by 11/20 interviewees**

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