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# Steps to build a thriving online patient community

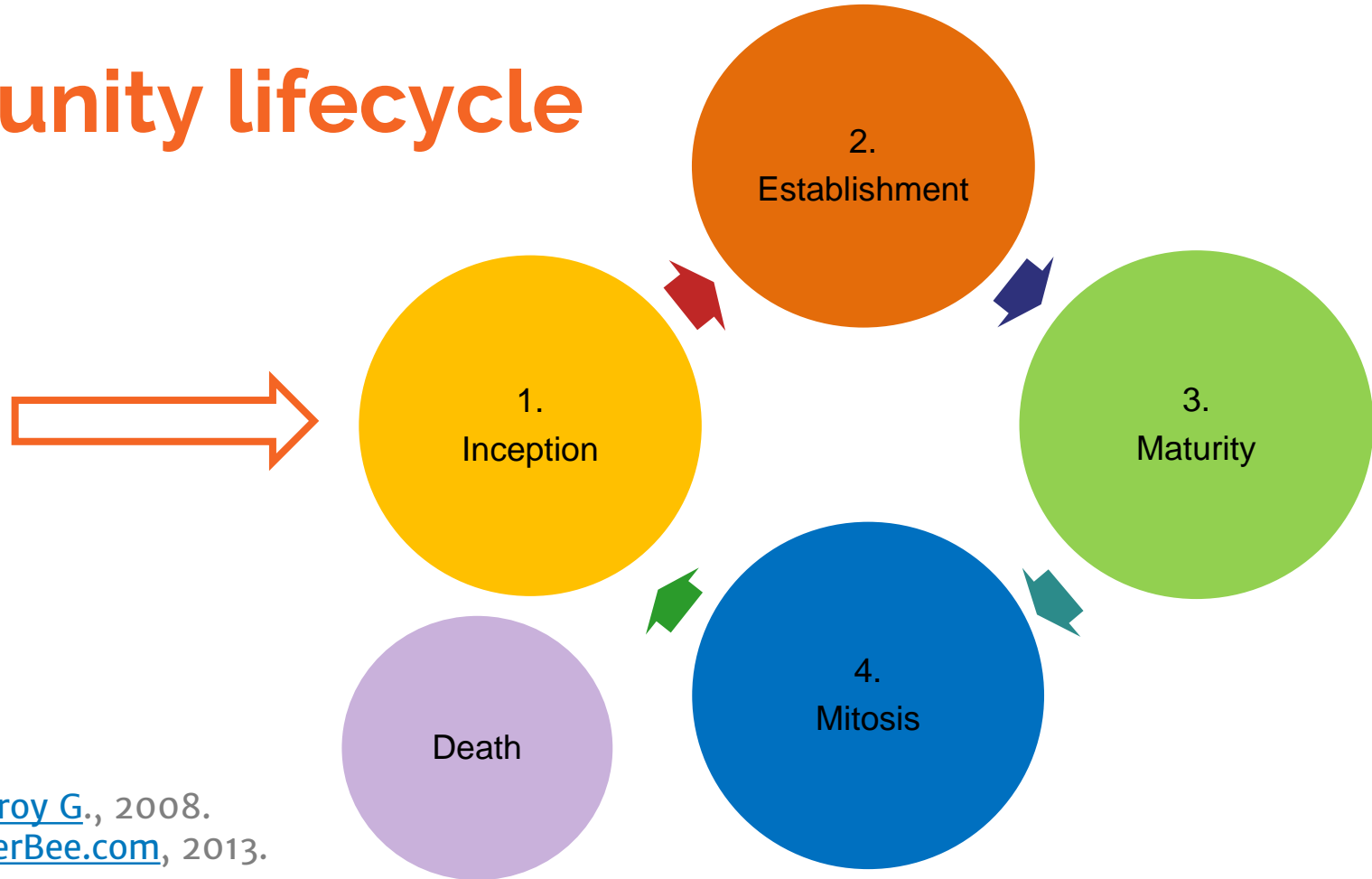
Colleen Young  
CY Connect, Online Community Strategist  
Mayo Clinic and SHSMD, June 3, 2020



A group of people who share a strong common interest, form relationships and interact online.

~ Sproull and Arriaga 2007

# Community lifecycle



Iriberry A. and Leroy G., 2008.  
Millington R. FeverBee.com, 2013.

# DEFINE DOMAIN & PURPOSE

The domain inspires people to contribute.

A clearly defined domain affirms the community's purpose and value to both members and your organization (funder).



# CONDUCT AN ENVIRONMENTAL SCAN

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Photo: <https://flic.kr/p/5d5d6B>



# DISCOVER INTERNAL EXPECTATIONS & ALLIES

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Photo: <https://flic.kr/p/91WQTK>

# SELECT YOUR FEATURE SET

Usability refers to how users interact with the technology.

It describes the user's experience with information design, navigation, access, and the dialogue and social supports, etc.

Online platform compare tool:

<https://www.feverbee.com/communityplatforms/>

# ENGAGE STRATEGICALLY

Sociability refers to how members of a community interact with each other.

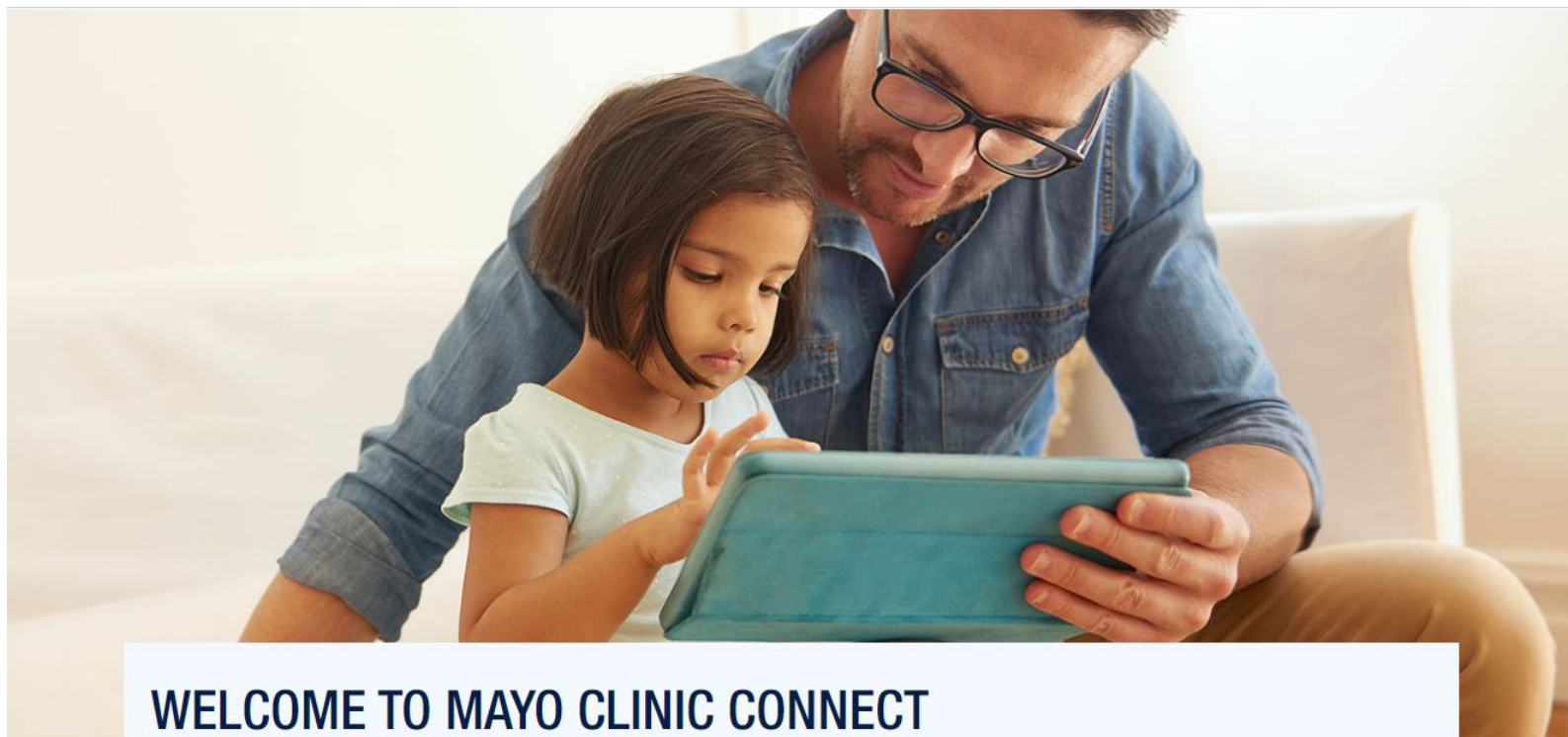
Human factor plus strategic community management.



# INTERVIEW PROSPECTIVE MEMBERS

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Photo: <https://flic.kr/p/LkLsU>



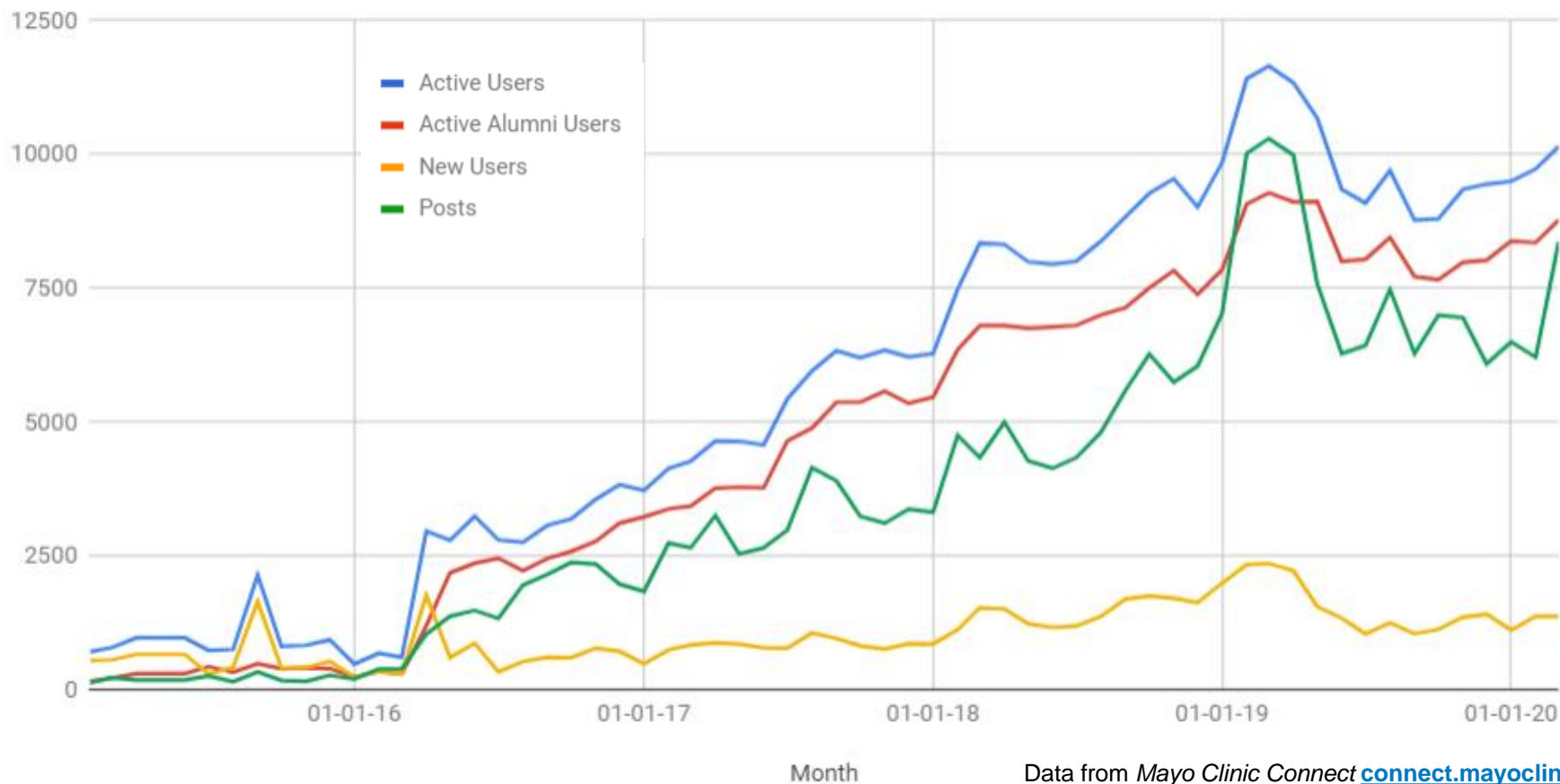
## WELCOME TO MAYO CLINIC CONNECT

Ask questions. Get answers. Connect.

Mayo Clinic Connect is an online community where you can share your experiences and find support from people like you. You can also read Mayo Clinic expert blogs and take part in educational events.

- [Join a Discussion Group](#)
- [How to Get Started on Connect](#)

# Story of a thriving community



Data from Mayo Clinic Connect [connect.mayoclinic.org](https://connect.mayoclinic.org)



Dawn Pereda

@dawnpereda

Posts: 46

Joined: Sep 27, 2017



## Adult Life after a Traumatic Brain Injury (TBI)

Posted by [Dawn Pereda](#) @dawnpereda, Sep 27, 2017

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Hi, My name is Dawn and I am an RN. Just over two years ago I received a work related injury. This injury has left me with a traumatic brain injury (TBI). Even though two years have passed, I still suffer with lingering tbi symptoms. I have some issues with memory. Some things I remember with no problems, other things I just don't remember and I can't explain why... I also suffer with issues related to mood dis-regulation. I can be angry at times and not understand why or end up having explosive outbursts. This has greatly impacted my life. I still work but no longer with patients. Also, this has been a huge turn around for my family. I'm no longer the mom who has everything under control. I used to work full time, manage my kids' schedules, pay household bills, and keep my house clean. Now I struggle to remember to brush my hair before leaving for work. My husband pays the bills and my kids write their schedules on a large calendar (that hangs in our dining room) so I can visually be reminded where they are and what they are doing. I am a "new" me and I never would have imagined this journey for myself.

I know there are things out there for youth that suffer from concussion/tbi, but I don't always find a lot of discussion/support for adults, like myself. I get up every day and work to live my life to its fullest. If you would like to know more about my life and journey, you can listen to a podcast that I did with my family. Its called "Terrible, Thanks For Asking". We're season 1, episode 5. Its brutally honest. If any of this rings true to your life please join this discussion with me. Thanks for your time!

Liked by [Colleen Young, Connect Director](#), [Kelly, Alumna Mentor](#), [vicki516](#), [Jamie Olson](#) ... [see all](#)

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MODERATOR

Colleen Young, Connect

Director

@colleenyoung

Posts: 8137

Joined: Jul 23, 2014



Posted by [Colleen Young, Connect Director](#) @colleenyoung, Sep 27, 2017

Hi Dawn, Thanks for starting this discussion. We have several members on Connect talking about living with and recovering from brain injury as an adult. I'd like to invite [@kdubois](#) [@cames](#) [@mattheschmatt](#) [@lakelifelady](#) [@beemerw47](#) [@jnewburn](#) [@suzyann](#) [@tech](#) [@danmlee](#) [@oceanfun1](#) [@janneg](#) and [@david33](#) in this discussion group about TBI.

Here's the link to Dawn's podcast "Terrible, Thanks for Asking" <https://www.apmpodcasts.org/tfa/2016/12/help-me-remember/> Here's how the podcast starts "A quick warning: this podcast contains references to sex, suicide and strong language..."

Dawn, as a nurse and uber-mom, it must be such a challenge to accept being the person who know longer has the oversight and everything under control. What things help you find peace with that or is that not possible right now?

# Mayo Clinic Connect's community strategy

GOAL IMPROVE HEALTH AND WELLBEING OF MEMBERS (self-management, self-advocacy, recovery, etc.)				
Objectives	Get members to set goals for improved self-management and recovery, and to share progress		Get top members (those who have been there) to respond, encourage and share their experiences	
Strategies	Make members feel proud as they improve, show progress and achieve goals.	Make members feel accepted to come back to the community if they have a setback.	Make members feel joy in giving back to help others.	Make members feel confident they have useful experience and expertise to share.
Tactics	Use gamification (badges and roles) for members to set targets and report progress.	Ensure every post gets a response, connect members and build a sense of belonging and give confidence.	Build the volunteer mentor program. Reward those who give back and inspire others to follow.	Recognize unique qualities of the superusers and show how they can contribute to the group.



Get answers &  
support they  
can't find  
anywhere else

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# Further learning

- C. Young. **Community Management That Works: How to Build and Sustain a Thriving Online Health Community** <https://www.jmir.org/2013/6/e119/>
- H. Safadi, E. Karahanna, T. Skousen, C. Young, S. Safadi, **Successful Moderation in Online Patient Communities: Inductive Case Study**, <https://www.jmir.org/2020/3/e15983>
- T Skousen, H Safadi, E Karahanna, F Chebib, C Young, **Tension Resolution and Sustaining Knowledge Flows in Online Communities** <https://bit.ly/3cVQDLT>
- C. Young. **I want my sex life back! TMI? Or gold for online community managers?** (blog) <https://bit.ly/2qeueRG>
- C. Young. **Don't Let These 3 Common Fears Stop You from Creating a Vibrant Patient Community** (blog) <https://mayocl.in/2Pcnnlb>
- C. Young. **Volunteer Mentors: The Secret Ingredient for Success of an Online Community** (blog) <https://mayocl.in/2VKpbYs>
- C. Young. **How Mayo Clinic's Patient Community Changes Health Care and Advances Science** (webinar) <https://mayocl.in/2A0XkOi>

# More questions? Let's connect



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