

Creating a Community with Mothers with Mental Illness Using Opioids

Joanne Nicholson, PhD, Shayna Mazel, MPP, Shannon Hennig, MA & Yaara Zisman-Ilani, PhD AHSR, Savannah, October 2018



Acknowledgements

- This project is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award #8285-BU.
- Resources & support from the Institute for Behavioral Health at the Heller School at Brandeis University
- MMHRC Key Partner
- No conflicts or disclosures





Objectives

- Following the presentation, participants will be able to explain the rationale behind mothers' engagement in various stages of research.
- At the conclusion of the presentation, participants will be able to describe two different strategies for engaging mothers with mental illness and opioid misuse in research development, implementation and the dissemination of findings.

- Closing the gap between research & advocacy
- Social media & online <u>research4moms.com</u>, <u>blog</u>, <u>Facebook</u>, <u>Twitter</u>, <u>Instagram</u>
- Patient Expert Advisors share content, connect with community, involvement in research projects





Mothers, Mental Illness & Opioids Project

- To engage mothers & researchers in virtual community development (*research4moms.com*)
- To provide online resources & infrastructure for knowledge exchange
- To implement a tailored, in-person community engagement studio model



Theoretical & Conceptual Building Blocks

- Knowledge exchange
- Virtual teams, collaboratories
- Stakeholder engagement
- Co-creation of research
- Open Innovation





Research Questions re: Digital Technology

- Digital vs. in-person therapies?
- Common elements of therapy in digital interventions?
- Increase reach & access?
- Overcome isolation?

(Hollis et al., The Lancet Psychiatry, 2018)





How to engage mothers with opioid use & researchers in the MMHRC community?

- How to address mothers' concerns, e.g., privacy, confidentiality?
- How to provide researchers with community engagement resources & support?
- Benefits & costs of virtual vs. in-person connections?



Community Engagement Strategies

- Social media initiative
 - Categorize, schedule & document postings
 - Manipulate the schedule
 - Explore response patterns with analytics
 - Dive deeper into comments
 - Engagement: likes, replies, shares & retweets
- Crowdsourcing with mothers & researchers to develop Research 101 and Mothers 101 resources
- Community Engagement Studios in-person model

Social Media Summary Data so far...

	June 2018	July 2018	August 2018	September 2018
Facebook				
New Page Followers	732	805	85	108
Total Page Followers	8509	9322	9407	9515

...



Post Details

MM:RC

Maternal Mental Health Research Collaborative - MMHRC Published by Hootsuite [7] · September 11 at 7:00 PM · C

Postpartum Depression Doesn't Just End After One Year http://ow.ly/hbpu30IEol4



Social Media Example:

Personal Experience - MH

RESEARCH4MOMS.COM

Postpartum Depression Doesn't Just End After One Year

Postpartum depression and other mood disorders are confusing. To start,...



BRANDEIS UNIVERSITY THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT INSTITUTE FOR BEHAVIORAL HEALTH



Post Details



Maternal Mental Health Research Collaborative - MMHRC

Published by Hootsulte [?] · September 16 at 1:01 PM · G

"Opioid addiction continues to impact the U.S. population at epidemic levels, and at a major cost to individuals and families as well as public health officials and even the labor force." http://ow.ly/2ngJ30IEopL



CDC: Number of Pregnant Women Addicted to Opioids Skyrocketed in 15 Years



Social Media Example:

Research - Opioids

BRANDEIS UNIVERSITY THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT INSTITUTE FOR BEHAVIORAL HEALTH



Example: Popular Press - Opioids

		_		_		
ы	63	ut.	٠	D	~	
					-	
	-				-	

Maternal Mental Health Research Collaborative - MMHRC Published by Hootsuite (?) · September 24 at 3:01 PM · @

"Stigma is a common barrier to care for pregnant drug users. Many people at the needle exchange said doctors treat them poorly, they're brusque or don't give enough local anesthetic, for example when they realize they are injection-drug users." http://ow.ly/YZdl30IEopV



THEATLANTIC.COM Pregnant and Addicted to Heroin

In Fresno County, drug use is about two times the state average. Pregnan...

1,251 people reached

Boost Post

You get what you deserve if you can't stop drugs for your baby or get on birth control to prevent getting pregnant while you're using you don't deserve sympathy

Like · Reply · Message · 1d



Maternal Mental Health Research Collaborative -MMHRC This comment isn't helpful or necessary and is EXACTLY why mothers who use drugs have issues accessing care.

Like · Reply · Commented on by MMHRC (?) · 23h

Maternal Mental Health Research

Collaborative - MMHRC then remove it if you don't like it. I stand by it. I don't believe in coddling people. Addiction is a crutch and making it seem like it's not in their power to change it is a disservice to people who actually struggle with addiction like me and like me, those who have overcome it and carry on with productive lives and become great parents. The only enemy is yourself the only one you can blame for your addiction is yourself, no matter what you went through or why you use its your fault entirely, you chose poor coping mechanism, chose to use and not get healthy and not seek treatment for mental health issues rather than using. If you feel guilty and ashamed that is on you and you probably should because you know what you're doing isn't right. If you find people judging you maybe it's not them it's you and your choices, taking responsibility is what needs to happen not a pat on the back and a good job. Sometimes the best thing that can happen to an addict is losing everything and especially those who enable the behavior by not setting ultimatums, the best thing that can happen is having people refuse to be around you and support your addiction. Sometimes its a kick in the gut but the truth isn't pretty and reality is harsh and a good dose of reality is what people need when it comes to addiction

Like · Reply · Message · 22h

Community Engagement Studios (CES)

- Promotes stakeholder input into research
- Community Navigator orients mothers & researchers to CES process
- Facilitator Guides group interactions
- Mothers provide input into researchers' questions



Crowdsourcing

- Mothers generate questions about research
- Researchers submit questions for mothers
- Researchers & mothers respond FYOL
- Responses posted
- jnicholson@brandeis.edu
- <u>mazel@brandeis.edu</u>

Reply in the comments

#mentalhealth via ripl.com 246 views BRANDEIS UNIVERSITY THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT INSTITUTE FOR BEHAVIORAL HEALTH



Research 101 Resources - Sample video



Do mothers have to share things they might consider personal?

Thanks!

Volunteer to record a video or pose a question to mothers. Contact us:

- jnicholson@brandeis.edu
- mazel@brandeis.edu
- <a>shannon@research4moms.com
- Yaara@temple.edu

Note: Images obtained from Google images, Pixabay and Shutterstock. No copyright infringement intended.



