MEDICINE X SOCIAL MEDIA PLAYBOOK

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Hi there, and welcome to the **Medicine X Social Media Playbook**.

In this guide, you will learn about how to handle and address matters and issues that regularly occur within the Medicine X Facebook Communities.

We have many, many communities running at the moment (over 70 global groups and counting), and each one of them have their own set of regular occurrences that ask for different responses and procedures.

This guide will help you understand what those occurrences are, how to spot them and most importantly teach you how to handle them.

So, without further ado ... let's jump in!

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Why does Medicine X have Facebook Support Groups?

Good question. Here's the answer:

Medicine X has created social communities based around individual disease states to better help the members in those groups learn about what their bodies are going through. While many doctors spend years and years studying texts and research cases and conducting interviews to better gain an understanding of what that particular disease is and does —that knowledge pales in comparison to the knowledge someone who *really* has the disease already contains.

The support groups were created so that people who live with and suffer through diseases everyday can have a place to connect with others who truly understand what they are going through.

Friends, family members, caretakers and patients alike, all are welcomed.

What are the Principles the Group is Built On?

The Medicine X Facebook Communities are built upon many beliefs and facets, but all of them boil down to the following:

Education. Any opportunity we have to offer deeper teaching or understanding –we take it! Misinformation is and always will be an uphill battle to combat, but the more education we spread, the farther it will go.

Support. Every group member has a story, and each of those stories we will never fully understand the depth of. That being said, treat every single group member that we correspond with with great care and gentleness. These are support communities, and the groups are here to allow all members to be heard, and for everyone to listen to each other's perspectives surrounding the disease state. Whatever the background or angle of the group member – your role as a member of Social Team is to be kind & supportive. When online, leave any and all bias at the door before you log in.

Encouragement. Living with a disease day after day is exhausting, draining and all together life changing. Group members have gone through a lot and will continue to go through a lot due to whatever illness they have --and sometimes they need a pick me up for their spirits. We can provide this through something as simple as a comment on their posts, or a reaction. A listening ear that lets them feel heard, noticed and cared for as a member of the group can make all the difference in some people. Don't be shy –let them know that you thought their post was funny/moving/heartfelt/shocking/relatable. A little bit of attention can go a long way in encouraging our group members :

Engagement. When the group is interacting with each other and posting regularly—that's a great day. Keep group members feeling like there is and will be something new every time they log back in. Encourage members to post again, or to "keep the group updated!" on posts that provide an update on their situations. Let new members know how welcome they are to the group and what kind of things they can expect to learn here in the groups. More than that, feel free to post into the groups (with the approval of a Community Manager) if you feel you have a stellar question to pose to the community to spark more engagement.

Let's talk about how to manage these groups, shall we?

How the Groups Work = Funded Groups Vs. Nonfunded P.O.C.'s

When it comes to the Medicine X Facebook Groups, there are two kinds of groups you should know about: <u>Funded</u> Groups, and <u>Nonfunded</u> Groups (also known as "Proof of Concept" groups).

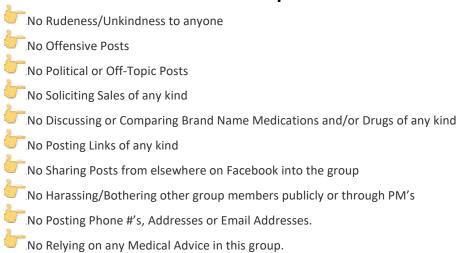
Funded Groups are the Medicine X Facebook Groups that have been paid for by a sponsor, and typically have a story either close to the end of development, or already have a story published.

Nonfunded Groups are all the other groups that are not funded. These groups are often referred to around the office as P.O.C. groups, or "Proof of Concept" communities.

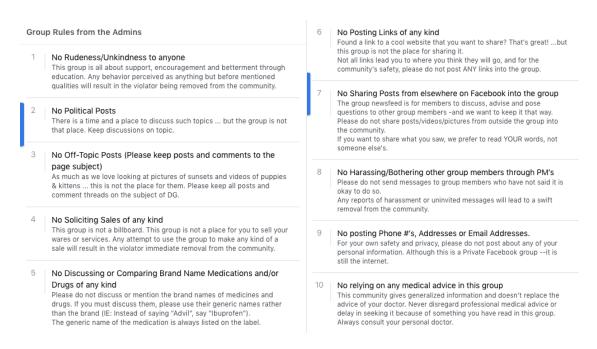
All groups start off as POC groups, and if we can find just the right fit with a sponsor, that is when a POC group makes the transition into a Funded Group. Groups that are Nonfunded/POC typically do not have stories being made just yet, but exceptions are made in some rare scenarios. POC Groups that are Nonfunded qualify in categories of "High-Level Groups", "Medium Level Groups", or even "Low Level Groups" to help Community Managers delegate their time appropratley when it comes to managing the large number of communities... but things change quickly and from time to time, a "Low Level Group" can easily grow and become a "High Level Group" in not much time at all.

Moderating the Medicine X Social Groups

The Group Rules



The rules that are active within the group (as of October 2018) are placed above and just below (as seen in the DG Xplained community). These are the rules that are seen within the community, and are enforced by the members of Social Team.



If/when you spy a group member who's posts or behavior violates any of the above rules, here's what you do:

- Identify: See the post and recognize how/why it violates any of the active rules.
- Remove: Take the post down (Delete/Remove Post).

- Message: Reach out to the OP (Original Poster) letting them know that their recent post was taken down due to it being against an active group rule
 - Notify & let them know which rule was broken.
 - Assure them no one is in any trouble, that this is just a friendly reminder \bigcirc .
 - Refer them to please take a look at the active rules list on the group's 'About' page.

If you wish, you can alert them that their post is in violation of group rules via the comments section of their post.

- Thank them for their post
- **Ask** them to edit their post to be more compliant with active group rules (IE: change their mention of a brand name drug to a generic).
- **Return** to confirm the change has been made (delete if no change made after an appropriate amount of time).

"One Strike ... You're Out!" Memberships

Memberships to the Medicine X Social Communities are a privilege, not a right.

Membership is not to be seen as a transaction-based service in which group members are entitled to *anything* from us. When a member decides to step up to you as a member of Social Team, they have the right to be heard, but not the right to be obeyed.

The Medicine X Social Communities are destinations provided by us to house safe conversation about a particular subject. Keep that in mind as we move through this next section.

Every now and again you will find that a group member has stepped out of their bounds and has broken one of the rules we have established. It unfortunately happens more often than you think...

We have a "One Strike & You're Out" policy in any/all of Medicine X's Facebook Groups. Violating any of the rules is a quick way for a member to:

- A) Have their post removed
- B) Have their Group Access Removed
- C) Have their Ability to Rejoin Any Medicine X Facebook Groups Revoked.

While we do enforce the "One Strike & You're Out" policy, we prefer to show compassion & leniency to group members, and often go off of proven track record. Letting members back into

the groups happens often and works as a solid learning opportunity for us to 'xplain' to them the rules & guidelines of the communities.

When a Member Breaks the Rules

After a group member has violated one or more of the rules and is not willing to comply with the rules in the future, the reaction on the side of the administrators (that's you \bigcirc) will be to block them & delete their posts from the group.

You can do this through the "Remove & Block" window that pops up to confirm that you wish to Remove & Block the group member from the community.

Removing & Blocking Members

Removing & Blocking is more often than not a black and white situation, but sometimes the line can be hard to see. If you are ever confused or unsure of what to do —ask a Community Manager.

After making the decision to Remove & Block, you may soon receive a message from that recently blocked individual for clarification as to why they were removed from the group. When this happens, even if you are not the one who blocked them, you can remind them of the rules and state that a member of the Social Team felt that a post or comment they made in the community violated one or more of the rules and has led to their membership being terminated.

They may try to convince you that they did nothing wrong, but you are not obligated to engage with them any further past letting them know that a member of the Social Team felt that a post or comment they made into the community violated one or more of the community rules.

Sometimes the banned individual in question may try to escalate the situation, and if/when that happens, forward the situation to a Community Manager.

Once again, the Medicine X Facebook Communities are <u>not in any way a "right" for anyone</u> to bully their way into. It is a privilege to be able to enter and engage with us and the other community members. Group members have not *paid* for anything, and they have not *done* anything deserving enough for them to be treated in any way that allows them to be rude to you as a member of the Social Team.

One last time, the Medicine X Facebook Communities are a privilege to be a part of ... not a right.

Interactions within the Communities

Crisis Protocol

As you patrol the communities, you may come across an event that is absolutely out of the ordinary, and may call for a special response that is outside of the realm of what can be planned.

Group members calling the police on each other, group members taking screenshots of other member's posts and messaging them to a group member's family & group member's trying to abolish religion from all of the communities (*all true stories* (all true stories)) are just a few examples of the unplanned phenomenon that one can expect to come across while patrolling the groups.

In these times, remain calm and do not get sucked into any of the conversations. Although you may be getting called out in the conversations ("Where are the Admins? Don't they care about us?", "Where is *tagged admin*?? They are terrible at responding..."), do not participate in the discussion.

Keep calm & slow down.

In times of chaos and downward-spiraling-dialogues, here's what to do:

- Identify the "fire starter": Find out what exactly sparked the questionable action/conversation.
- o **Identify who started the "fire"**: who was it that single handedly started all the commotion? (This is important because they may need to be removed from the group due to how dangerously zealous they may be toward whatever topic they started discussion on).
- Contain the "fire": Isolate the areas of the website where the conversations are taking place (turn off commenting, delete inflammatory posts/comments).
- O Release statement about the "fire" after it has been put out: After removing the necessary group members and deleting the inflammatory posts/comments from the newsfeed, it is prudent to reassure the remaining group members that the Social Team has a strong presence in the community. A post addressing the series of events that just happened is required after an ordeal occurs, and should come from a Community Manager.

Typical Commenting/Reacting

We want group members to each feel that they are heard and appreciated. We can do this in several simple ways.

• Comment that we are happy they have joined the community and conversation.

- Respond in an "active listening" manner by commenting messages of condolence if their post is of a sad nature, or excitement if they are sharing a post of good news.
- Feel free to emoji it up () in your responses but try not to have emoji be unaccompanied by text. We want community members to feel that they are being heard, and that their words are actually being read.
- React to their post (Like/Love/Laugh/Shock...)

Posting

Posting in the groups is done by the Community Managers, and only the Community Managers unless otherwise delegated.

This is so that we don't have multiple people all trying to flood the newsfeed. There is a method to our posting, and that method is up to the Community Manager.

If you have an idea for a post, great! It will more than likely become a live post! ...but don't just go and post it yourself –run it by the Community Manager so that it does not conflict with any pre-existing scheduled posts he/she may have going live soon.

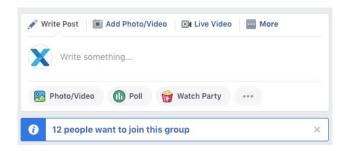
Any and all posts should be comprised of two basic things:

- A visual of some kind (Picture or Video)
- Accompanying Text

There should not be any posts that go live that have one without the other. If you as a member of Social Team spot a post that is missing one or the other, please notify a Community Manager.

Accepting/Denying Invites

The only way members can join the social communities & start viewing posts is through an invite acceptance. Potential members see that our group exists and if interested in joining, they ask via Facebook for permission to join.



Their Facebook profile is then sent to Group Admins in that desired group and then "Accepted" or "Denied" admittance into the group.

The minimum criteria for acceptance into the groups are the following:

- They are located in the US*
- The Facebook profile has existed longer than a few months*
- The profile seems legitimate and not "spammy"

Welcoming Group Members

After a bit of time (sometimes as little as a few days, and sometimes as long as a few weeks) you will find that a particular community has grown quite a bit. In these instances, a "Welcome Post" is in order. These posts are designed to get conversations started and to help the new members feel that they really are a part of a community, and not just a quiet & invisible spectator.

A feature that Facebook has created allows us to tag the newest group members (up to 100 members at a time) and include them in a post geared to welcome them. Add a brief intro message, attach a welcoming image and post it to let the group know we say "Hey! (1) ... but of course, ask a Community Manager before posting!



^{*=} exceptions may be made from time to time, so check in with a Community Manager if unsure.

Spammers (members who only post links)

You will find that many links are posted into the groups on a daily basis, sometimes by accident (people who just don't know the rules just yet) ...and sometimes not so much by accident.

Some websites get their links posted into the groups on a regular basis by "spam" accounts, profiles that were created just to post website links and lure our group members away to be sold to, defrauded and/or taken advantage of. To protect our members, we mark the post as SPAM (An option in the "Give Feedback tab"), delete the links right away & ban the profile used.



Reported Posts

Members in the community have the ability to help us out and flag posts that they feel should receive a second look from Social Team members. These flagged posts often get sent to us because a group member feels it violates the group rules in some way.

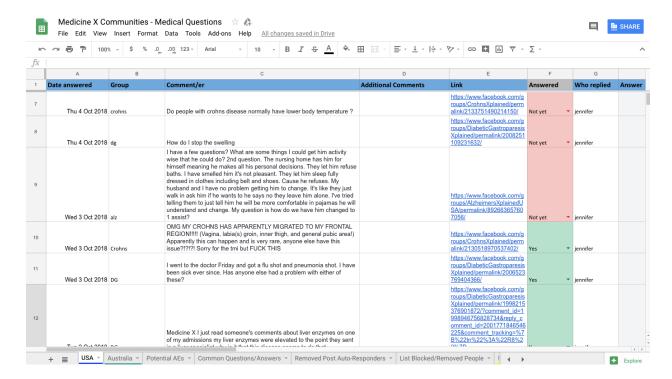
This is a super helpful tool that we wish more group members utilized, but it can also be used accidentally, as a perfectly acceptable post may be occasionally flagged as a reported post. Either way, when you see the red box marked "REPORTED POST", please perform due diligence and check it out.



Medical Questions

One of the many benefits of the groups is that community members have access to our Medical Team, with which they can directly ask questions to and interact with in real time.

Because the members of Medicine X's Medical Team's time is precious (we have their attention spread all over!), the Social Team uses a log of medical questions that members of the Medical Team check throughout the day. This log can be found with a Community Manager, and can also be found HERE.



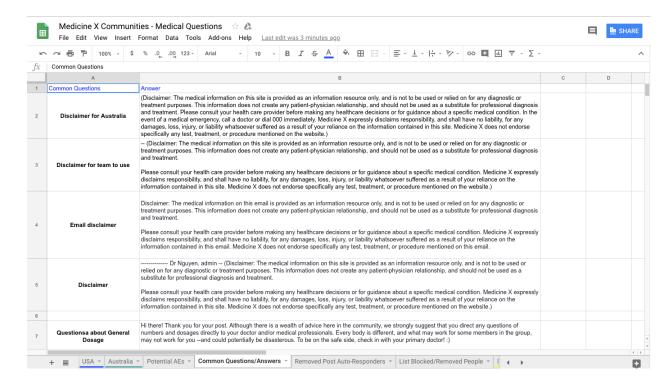
This log is where members of the Social Team link questions they see asked in the group, and when placed on the log, it will be answered by a member of the Medical Team as soon as possible. Just one of the many awesome perks of being a Medicine X Community Member!

Common Questions (Pre-Written Responses)

Part of being on the Social Team, and not the Medical Team, is that we cannot directly provide medical advice. Only members of the Medical Team are allowed to safely give that kind of advice, as they are licensed to do so.

When you see a question or comment posted into one of the groups that is seeking a medical opinion, you can link that post/comment onto the Medical Questions Spreadsheet, or send a link to the post/comment to a member of the Medical team via Slack or email.

If you notice that a particular medical question continues to pop up over and over again throughout the group, feel free to ask a member of the Medical Team for an approved Copy+Paste response that you can use whenever that question pops up again. You can view a created list of Pre Written Medical Responses HERE.



Disclaimers

To protect the members of the Medical Team, as well as any member of the Social Team, we have disclaimers set up throughout the communities. When a member of the Medical Team posts a reply to a medical question, it is typically followed with a disclaimer similar to:

"This community gives generalized information and doesn't replace the advice of your doctor. Never disregard professional medical advice or delay in seeking it because of something you have read in this group. Always consult your personal doctor."

Disclaimers keep you, and other Medicine X team members, safe from possible risky behavior. If you have any questions about disclaimers, feel free to ask one of the Community Managers for clarification.

Suicidal or Self-Harm Post Reactions

Medicine X has a small handful of groups that address mental health issues. These are groups that require extra levels of sensitivity.

Along with being able to offer a listening ear and to encourage sharing into the groups, you as a member of the Social Team may come across a post that contains references to self-harm, substance abuse or even intentions of suicide.

If/when you come across this kind of content within the groups, besides notifying a Community Manager, you are required to do the following:

- Respond publicly to their post/comment the appropriate information on how to contact a member of the Suicide Prevention Team (IE a Phone # (US <u>1-800-273-8255</u>) to call and/or a link to an online Live Chat (http://www.suicidepreventionlifeline.org/GetHelp/LifelineChat.aspx)).
- Respond privately: Direct Message the individual to check in on them and also provide the same contact information for them to get in touch with a member of the Suicide Prevention Team.

Preservation of Privacy within the Groups

Privacy is one of the pillars of the Medicine X online communities. Group members need to feel comfortable to share and speak openly about what they are going thorough without fear that what they have to say will be used against them in any way, or be seen by disapproving eyes.

To preserve this privacy, Medicine X makes every effort to ensure that no information is allowed to exit the community. This includes (but is not limited to)

- Screenshots
- Taking photographs of the screen
- Logging into the group and showing non-members what is happening in the community
- o Discussing what is occurring within the group in real life with non-members
- Reaching out to friends of group members to alert them to what is being said within the private community

Anytime you as a member of the Social Team come across a situation in which you feel another group member's rights to privacy has been violated, inform a Community Manager right away, and they will work to rectify the situation ASAP.

Adverse Event Reporting

As you move through the group, you should be on the lookout for several points of interest that we as Social Team members need to be on the lookout for. Anything that violates the community rules & guidelines is one thing, but more than that are potential <u>Adverse Events</u>.

An **Adverse Event** is any negative outcome that is caused by a product by any one of Medicine X's pharmaceutical focused partners. Whenever a medicine created by one of our pharmaceutical focused partners is mentioned, it deserves to be treated carefully, and if one of the Clinical Trials medicines is mentioned, it needs to be officially reported through the proper channels.

Adverse Event Keywords (as of October 2018):

- o Relamorelin (Associated with DG)
- Atogepant (Associated with Migraines)
- Ubrogepant (Associated with Migraines)
- Brazikumab (Associated with Crohn's & UC)

If you come across any medicine names of any Clinically Trialed drugs (<u>or any attempts to describe them</u>), report it to a Community Manager as soon as possible so that they can begin the necessary steps of properly reporting it.

<u>UPDATE</u>: To assist in the Social Team's endeavor to monitor for potential adverse events, Medicine X uses *Archive Social*, a live searching program that scans all linked Facebook groups for input keywords and phrases, and notifies all listed personnel accordingly. Ask a Community Manager to learn more about *Archive Social*, today!

The Groups (An often updated list)

As mentioned before, there are plenty of groups all waiting to be moderated by the Social Team. Although there may be a lot, and each group asks for a very different persona of interaction --how we as the Social Team interact with the groups remains constant.

Here is a list of the Medicine X Facebook communities in full (as of September 20th).

The Funded Groups

Funded groups are groups that Medicine X has attached to a funded contract. When that happens, an "Xplained" story is typically on its way to being published! As of late 2018, the following groups have become funded and signed onto a contract:

- <u>Diabetic Gastroparesis</u>
- <u>Migraine</u>
- Alzheimer's
- <u>Ulcerative Colitis</u>
- Crohn's
- Acute Lymphoblastic Leukemia
- Clinical Trials

High-level Groups

We also have High Level groups that do not have contracts just yet, but are very close to being signed onto one. This proximity to becoming a funded community is what makes the following groups have the significance that they do:

- Macular Degeneration
- <u>Lupus</u>
- COPD
- NASH
- Fatty Liver
- Heart Failure
- Leber Congenital Amaurosis
- Vision Impairment
- Multiple Myeloma
- Type 2 Diabetes
- Lupus
- Chronic Pancreatitis
- CRISPR
- Rheumatoid Arthritis
- Colonoscopy

Mid-level Groups

From there, we have **Mid-level** groups, or groups that are in that middle ground of becoming a signable option, but not quite there yet. As of October 15th, those groups are:

- Aortic Stenosis
- Atrial Fibrillation
- Diabetic Kidney Disease
- Chronic Pain
- <u>Depression</u>
- Flu Vaccination
- Metastatic Breast Cancer

Low-level Groups

Finally, we have **Low level** groups, and these are groups that have very few members inside of them and are currently not attached to any contract or have plans to be attached any time in the immediate future. Regardless, these groups are still deserving of love. Those groups (as of September 20th) are:

- Grief
- Osteoarthritis
- Major Depressive Disorder
- Irritable Bowel w/ Constipation
- Juvenile Idiopathic Arthritis
- Psoriasis
- Overweight
- Metastatic Melanoma
- Metabolic Syndrome
- Epilepsy
- Colostomy
- Sarcoma
- Back Pain Xplained
- Ileostomy
- NETs
- AML
- Fecal Transplant

Please refer to the Hierarchy of Group Moderation. It can be found (as of September 20th) in the Google Sheet here.