

# Reducing intracommunity harm and creating collectiveness in online communities through co-design

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## Abstract

Online communities have been shown to have substantial benefits for individuals, specifically for those who experience forms of physical and social isolation. However, they can also be an avenue for further harm and exclusion to occur, especially for individuals who already experience levels of systemic, societal, and personal marginalization in their day-to-day lives. In this qualitative study, I explore the particular benefits, disempowerments, and limitations of one type of online community that has emerged in recent years: for those who still take COVID-19 precautions, such as wearing high-quality respirators in public, and care about limiting the spread of COVID-19 and other airborne illnesses while living in a world where the majority have moved on from the ongoing COVID-19 pandemic. Using interviews and group co-design workshops, I engaged with 10 individuals who still take COVID-19 precautions and are a member of at least one of these online communities. The findings of this study highlight the unique intersectional lived experiences of these individuals and the most pressing needs they see within their community. I discuss the use of synchronous co-design workshops as a potential method for members of online communities to identify shared goals, principles, structure, and processes to reduce intracommunity harm and begin building a more collective community.

## Acknowledgements

I am grateful to live and learn on the ancestral lands of the Indigenous peoples. This research was conducted in t'karonto, and with deep consideration, I acknowledge the ancestral territories of the Mississaugas of the Credit, the Haudenosaunee, the Anishinaabeg, and the Huron-Wendat, who are the original owners and custodians of the land on which we stand and create. I acknowledge their position as primary witnesses to the rapidly changing physical environment I am situated in, relying on us all to be worthy co-stewards and keepers of the beloved spaces where we live, work, and create; together facing the responsibility and realities of this shared legacy. I also acknowledge the Métis, Inuit, and Indigenous urban communities who share these lands.

I also extend my gratitude to the OCAD U SGS Project Grant and SGS MRP Support Grant for their financial support, which has made this research possible and provided ability to compensate collaborators.

## Dedication

First and foremost, I want to **thank Pia Berger, Faelix Kayn, Alyson Hardwick, and the rest of the collaborators**. This research project would not have happened without you! I hope this project honours your stories, vulnerability, perspectives, intellect, and hopes for a better future. Thank you all for the immense amount of care and thoughtfulness you bring to this topic, to protecting others and your community, and to protecting yourself.

Thank you to **Dr. Michelle Wyndham-West**, my primary advisor and program director of Inclusive Design. Your guidance and expertise have helped me shape this project into what it is. Your own research work inspired me to give voices to those who do not traditionally have one. Thank you for all your work with me and motivation to keep going and meet deadlines.

Thank you to **my parents, Joey, Eril, Maayan, and Carl** for your support throughout my pursuance of this degree and this project. You all have inspired and motivated me at different times and given me the belief in myself that I sometimes (okay, often) lacked. Thank you for being there when I needed you, even during difficult times, holding me accountable to get work done, letting me bounce ideas off you, helping out with other life stressors, and providing reassurance given the state of the world. I couldn't have done this without each of you.

Lastly, this project is for everyone who has ever felt alone and held despair, especially for those who still live with the reality of the ongoing COVID-19 pandemic and genocide in Palestine. I hope this project makes you feel a little less alone, and you take something away in terms of the importance of community care, Disability Justice, and creating a collective future you want to see.

“How can we cultivate spaces where everyone has that soaring sense of inclusion, where we can have difficult and meaningful conversations?”

— s.e. smith

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## Statement of Contributions

I want to thank Pia Berger, Faelix Kayn, Alyson Hardwick and all other collaborators who have decided to remain anonymous for the following contributions in this project:

- Sharing their lived experiences and vulnerable stories with me and those reading this research
- Participating in and co-facilitating the co-design workshops
- Contributing their ideas, unique perspectives, and imaginative futures
- Being respectful of each other and their opposing perspectives
- Their passion in the topic
- Reviewing and revising their quotes and references used to ensure their voice is representative of them and their experiences

# Introduction

## Background

With the rise of the Internet and social media, online communities have exploded in the 21st century for people to find social connectedness and support with others from around the world. There is no singular definition of ‘online communities.’ Rheingold (2000) defines them as “cultural aggregations that emerge when enough people bump into each other often enough in cyberspace,” whereas Preece (2001) has a more purposeful definition as “any virtual social space where people come together to get and give information or support, to learn, or to find company.” People seek these online communities for many reasons, whether that is to relate and bond over a particular interest, or to seek a safe space and support related to a marginalized identity or health issue, for example. Online communities often go through a common lifecycle depending on its success, starting with its inception and low levels of engagement, to becoming more established with a limited number of committed members, then maturing with high engagement and strong sense of community, and sometimes mitosis where the community splits into more focused subgroups (Young, 2013). Online communities are more likely to fail and fall apart in the earlier stages where there is lower growth, engagement, and sense of community (Iriberry & Leroy, 2009). Depending on the platform and type of community, some are moderated and governed heavily by one or multiple people, whereas others have no governance and are an open public forum.

Whatever the model of maintenance and governance, all are still at risk of creating exclusive, hostile environments, especially due to the nature of the Internet and online disinhibition (Suler, 2004). There are several studies that expose exclusion and intracommunity harm, particularly towards people of multiple intersectional marginalized identities (Alhaboby et al., 2023; Barakt & Redmiles, 2022; Gray, 2012; Miller, 2017; Walker & DeVito, 2020). I am interested in exploring how members of an online community can work together to improve inclusivity and belonging through co-design and participatory approaches, rather than the common oligarchical model, or the opposite “free for all” model.

To explore this area of inquiry, I wanted to engage with a specific type of online community that has only emerged in the last few years and has yet to be researched. These online communities are for people who still take COVID-19 precautions outside of the yearly vaccine update to protect themselves and others, such as wearing high-quality respirators (e.g., N95s) in public at all times, limiting exposure to others, and in some cases, isolating themselves due to the lack of public health measures and continuous high rates of COVID-19. A recent study by Pew Research in March 2024 shows that 1 in 5 Americans say COVID-19 is still a major threat to public health, 27% are very or somewhat concerned about being hospitalized from COVID-19, and 40% are very or somewhat about unknowingly spreading COVID-19 to others (Tyson & Pasquini, 2024). The physical and social isolation of people still taking pandemic precautions has led to hundreds of localized online communities for those to ask questions, share resources, and connect with others on their shared experiences. In this study, I seek to not only listen to and share individuals' stories and experiences in relation to this physical/social isolation, but to understand these unique COVID-cautious (CC) online communities, how they have helped individuals, how exclusion and intracommunity harm have occurred in these communities, and how co-design could be used as a tool to improve organization of online communities.

## Research questions

This research study is guided by primary and several secondary research questions to explore these inquiries.

### Primary research question

How can an online community that is *intended* to be an inclusive, safe space be improved to reduce intracommunity harm and foster further connectedness through community involvement and co-design?

## Secondary research questions

- What are the lived experiences of people who are physically/socially isolated and excluded due to their disability, immunocompromised status, or concern for their health and others in regard to COVID-19?
- How have online communities helped individuals who are physically and socially isolated due to health conditions and concerns of COVID-19?
- How has intracommunity harm and marginalization occurred in these online communities for people who take COVID-19 precautions?
- How does intersectionality of race, gender, class, culture, age, etc. play a role in those lived experiences and intracommunity harm?
- What are examples or ideas of approaches taken to create an inclusive online community environment? What has worked/not worked?
- What are the most pressing needs community members see for their community? How do community members want to organize themselves to achieve these needs?

## Review of the literature

### Benefits of online communities

There are many studies that show positive effects and benefits of online communities. A large area of research has looked at online communities for specific health or chronic illness-related support groups. Allen et al. (2016) conducted a meta-synthesis of 21 qualitative papers that examined the use of peer-led online communities for those with a long-term condition. Nearly all the studies included in this meta-synthesis conducted a content or thematic analysis of messages and postings in disease-specific discussion boards and forums and did not speak to individuals regarding their experiences. Two studies included in the meta-synthesis conducted online surveys with people who use online communities for disease-specific support, but none spoke directly with community members. The most common and notable themes found in relation to benefits of online communities were emotional support and cathartic sharing, feelings of solidarity, mitigating

loneliness and isolation, sharing information and knowledge, breaking offline limitations such as temporal, spatial, and geographical, establishing relationships, and promoting a diverse community with an inclusive culture. These benefits are shown to have positive effects on individuals' well-being and psychological relief, especially in response to the physical and social isolation that comes from long-term conditions and the lack of support or information they receive from medical professionals (Allen et al., 2016). I am interested in exploring the overlap of these benefits within COVID-cautious (CC) online communities and discovering potentially new benefits not found within existing research.

### Limitations, disempowerment, and exclusion in online communities

While there are many benefits of online communities, there are also some limitations to online communities compared to in-person communities. A study which conducted an online survey with HIV-related online support group members identified lack of physical presence as being a detriment to the ability to form relationships online, particularly when it comes to conveying emotions or understanding the exact meaning of a comment. Inappropriate or disrespectful behavior sometimes occurred due to anonymity, making members feel personally attacked or ridiculed for their opinions and leading to feelings of mistrust and fear. Also, misinformation or information overload lessened the value of online communities for some, as there were concerns of inaccuracy, as well as too much information being daunting (Mo & Coulson, 2014).

Other studies have looked at how exclusion due to members' marginalized identities has occurred in online communities. One study surfaced the oppressions women of color experience in Xbox Live, an online gaming community, through ethnographic observations and narrative interviewing (Gray, 2012). Online gaming communities are comprised of primarily white cis men, and this study revealed the racism and sexism in these communities when women and non-white people try to join, particularly due to linguistic profiling, or sounding feminine/non-white. This led to women of color having to create their own intentional safe spaces for gaming and being strict about who was allowed into the group to keep racism, sexism, heterosexism, and nativism out (Gray, 2012). Another study illustrated

intracommunity power dynamics and harm in online LGBTQ+ spaces through qualitative probes and interviews (Walker & DeVito, 2020). While these spaces seem to be inclusive due to the identity of being LGBTQ+, there is significant evidence of individuals experiencing harm within these communities based on other marginalized identities and factors such as race, socioeconomic status, bi+ identity, and trans identity. This study revealed how existing societal structures related to proximity to power are also replicated online in these spaces. It also surfaced conflicts that are native to online spaces, such as establishing trust and “talking past one another,” which can escalate to harm (Walker & DeVito, 2020, p. 9). Another qualitative study exploring the impact of social media on identity-making for queer and disabled students found that participants had to weigh the positive and negative effects of being part of online communities (Miller, 2017). Though they experienced racism, feelings of isolation, and negativity in online spaces, there were also many benefits such as exploring new identities, raising political awareness, helping others, and managing stigma (Miller, 2017).

## Online disinhibition

The way people show up and act on the Internet is often outside the norm of how they would regularly behave in-person. This behavior is coined ‘the online disinhibition effect,’ which can explain why people may be able to express things more openly on the Internet, as well as why trolling, harassment, and cyberbullying is so common. The online disinhibition effect outlines six factors involved as to why this occurs: dissociative anonymity, invisibility, asynchronicity, solipsistic introjection (the absence of face-to-face cues), dissociative imagination, and minimization of status and authority (Suler, 2004). While inappropriate behavior and acts of marginalization in online communities can be explained by the online disinhibition effect, some of these factors are also shown to contribute to positive outcomes or benign disinhibition. Allen et al. (2016) demonstrates that many people feel more comfortable reaching out for support for their long-term conditions online, particularly due to the factors of dissociative anonymity, invisibility, and minimization of status and authority.

The online disinhibition effect will be considered and referred to during analysis of this study to explain why certain behaviors may take place.

### Suggestions and frameworks for thriving and inclusive online communities

Within the studies that expose the exclusion and marginalization that occur in online communities, there are a number of suggestions from these findings on how designers, moderators, and community members can create more inclusive and thriving online communities. An important first step identified to decrease this harm is to center the voices of marginalized communities in online spaces (Walker & DeVito, 2020). Designers of online community platforms and spaces need to “consider how sociotechnical systems can reify and amplify power dynamics” and be aware of how their biases may contribute to upholding the power dynamics that lead to harm towards the most marginalized (Walker & DeVito, 2020, p. 10). In addition, there should be a focus on moral values during the design process. In studies on values, ethics, and policy in the context of online communities, there is an argument for ethics and policy research to be integrated into the design team at an early stage because policy concerns inevitably emerge within these online spaces (Centivany, 2016; Centivany & Glushko, 2016). Lastly, Dosis (2014) proposes three grounding principles for designers as a framework to designing inclusive online health communities: sociability, hospitality, and equability. These principles refer to considering the community members’ needs and purposes of the community as a whole, the members feeling welcomed and at ease throughout their interactions within the community, and how adaptable and accessible the community is for diverse members (Dosis, 2014).

With the Internet, technology, and society as a whole rapidly changing throughout the 21st century, so do the needs and wants of people. Iriberry & Leroy (2009) proposed the lifecycle of an online community and was adapted by Young (2013) with four stages: inception, establishment, maturity, and mitosis, adoption or death. These stages are not linear and “community management goals, strategies, priorities, and basic tasks will evolve” (Young, 2013, p. 5). Thus, a successful and inclusive community should be designed for a high level of flexibility to evolve with the constant-changing needs of its members (Basdekis et al.,

2006). Studies propose surveys as an effective tool to gather feedback and assess how an online community can change based on its members needs and wants (Dosis, 2014; Young, 2013). However, there is risk of bias with members likely to respond to surveys are often the most engaged community members (Young, 2013). Surveys also are not likely to grasp the full experiences of community members, particularly marginalized members, and miss areas of exclusion and harm that is being caused due to a lack of safety from those members.

Moderators of online communities take on a huge toll of deciding how to handle harm and conflict, and this holds a certain power. In the case of Reddit and its democratic design, moderators "are the users who occupy the best position to be able to advise, critique, or direct the political response of Reddit in the face of controversy" (Centivany & Glushko, 2016, p. 1132). Moderators have the authority to ban or block users, "however, these tools can exacerbate harms that arise from intracommunity conflicts, especially if a larger societal power dynamic puts the tools in the hands of the already powerful" (Walker & DeVito, 2020, p. 10). Diversifying moderation teams can help with this imbalance of power, biases, and decision-fatigue, as well as providing alternatives to bans or blocks for resolving disagreements. Walker & DeVito (2020) recommends an "educator-moderator" role that can intervene with individuals displaying harm or conflict, while compensating and empowering marginalized individuals (p. 10).

### Community-led moderation, co-creation, and participatory policymaking in online communities

There are many informal ways in which non-moderator community members take initiative on forming the culture and dynamics of community, co-creating resources and information, and moderating/self-moderating content. Health and chronic illness-related communities were shown to co-create records of information and knowledge based on lived experiences and the ability to easily request, receive, and search for that information. This proved immense value for community members, although sometimes there is information overload that would require members to assist in navigating to specific resources (Allen et al., 2016).

The more beneficial and supportive community members deem an online community to be, the more likely they exhibit “online community citizenship behavior (OCCB),” such as “information sharing, knowledge contribution, topic discussion, community interaction, among others” (Liu et al., 2020, p. 2). Thus, the stronger an identity they have with a community, the more obligated they will feel to maintain community development and work to create sustainable values (Liu et al., 2020).

There is also evidence in which community members moderate others and display acts of self-moderation, particularly in supportive and more inclusive online communities. In an online self-harm forum for young adults, posters took on the role of experts by demonstrating expectations of norms and boundary-setting, despite the presence of trained moderators (Smithson et al., 2011). A study analyzing the posts of a large online public forum for sex workers found that members assisted moderators’ efforts in enforcing forum rules and self-moderating by prefacing their posts and obfuscating triggering content (Barakat & Redmiles, 2022). In the case of Reddit and explored in studies related to controversial topics on Reddit, users exercise a form of moderation through the democratic design of “up voting” and “down voting” a comment to raise or subtract its visibility and prominence (Centivany, 2016, p. 6). However, in the face of these controversies, users expressed demand to have more of a role in the governance and policy impacting the community rather than just supplying and moderating the content (Centivany & Glushko, 2016). Centivany & Glushko (2016) coin the term “participatory policymaking” as a way forward for users in highly participatory communities to have a say in the overall platform’s policies and design (p. 1126).

While these are all asynchronous examples of community involvement, participatory moderation, and co-creation in online communities, there are no studies conducted on utilizing synchronous participatory co-design methods with members of an online community, particularly when it comes to addressing intracommunity harm and exclusion. One protocol for a study to understand older adults’ needs in online health communities proposed co-design as a method, however, there is no evidence the study was carried out (Lawless et al., 2020). Understanding how a synchronous co-design approach in creating

inclusive online spaces works could open up avenues for designers, moderators, and community members of online communities.

## Methods

Primary methods were semi-structured virtual hour-long interviews and three separate group co-design workshops with 10 collaborators/participants. Semi-structured interviews are a qualitative data method where the researcher has “a series of predetermined but open-ended questions” (Given, 2008, p. 810). Co-design is a method “actively engaging a broad range of people directly involved in an issue, place or process in its design and sometimes also in its implementation” (Burkett, 2012, p. 4). Analysis involved a combination of reflexive thematic analysis, constructivist grounded theory, and interpretative phenomenological analysis (Braun & Clarke, 2019, p. 589; Eatough & Smith, 2017, p. 193; Given, 2008, p. 376). Procedures were reviewed by the OCAD Ethics Board.

## Collaborators

Collaborators were recruited via a Facebook group with permission from the moderator and personal group chats I am in for people who self-identify as “COVID-cautious” (CC) or “COVID-conscious/informed/safe/aware.” Respondents were asked to describe the COVID-19 precautions they currently take and identify if they currently are or have been a member of an online community related to the ongoing COVID-19 pandemic. To recruit a diverse range of collaborators and to understand how intersectional identities play a role in experiences related to COVID-19 and online communities, respondents were asked to self-identify their age range, pronouns, race/ethnicity, location, and if they self-identify as 2SLGTBQIA+. Due to the nature of the online groups and group chats I am a member of, there may be a bias in the perspectives of people interested in participating in the study. These groups tend to have younger members (20–40-year-olds) and members tend to engage in political and justice-oriented discussions and events.

Of the 10 collaborators selected, two are in the age range 18-24, six are in the age range 25-34, and two are in the age range 35-44. Of the 10 collaborators, seven use the pronouns she/her, two use the pronouns they/them, and one uses the pronouns he/him. The sample of collaborators is predominantly white (four; one secular Jew). Other collaborators self-identified as Black/East African/Somali/Muslim (one), South Asian/Indian Muslim (one), East Asian (one), and three are biracial—white/Middle Eastern (one), white/Latin/Mexican (one), white/Indigenous/Inuk (one). A majority of collaborators self-identified as 2SLGBTQIA+ (six). With regards to disability, three collaborators identify as having a physical disability or being chronically ill/immunocompromised, four identify as having a mental disability, two identify as currently having Long COVID, a chronic condition with a wide range of symptoms that occurs after a COVID-19 infection and is present for at least three months, and one has recovered from Long COVID (U.S. Centers for Disease Control and Prevention, 2025). During the interviews, two collaborators self-identified as low-income. In terms of where collaborators are settled, seven collaborators are located in Toronto/t'karonto, two are located in cities in Ontario/kanadorio, and one is located in western Canada/kanada. All identity categories are self-identified, and I did not impose an identity among any collaborator. See Table 1 for a summary of collaborators' self-identified characteristics.

**Table 1:** *Summary of collaborators' self-identified characteristics*

Collaborator characteristics	Number
Age	
18-24	2
25-34	6
35-44	2
Pronouns	
She/her	7
They/them	2
He/him	1
Race/ethnicity	
White	4
Secular Jew	1
Black/East African/Somali/Muslim	1

South Asian/Indian Muslim	1
East Asian	1
White/Middle Eastern	1
White/Latin/Mexican	1
White/Indigenous/Inuk	1
Identify as 2SLGBTQIA+	6
Disabilities	
Physical disability/chronically ill/ immunocompromised	3
Mental disability	4
Long COVID	3
Current	2
Recovered	1
Low-income	2

All of the collaborators ongoing COVID-19 precautions include wearing a KN95, N95, or better respirator in all indoor public spaces and typically outdoors too. Other precautions include using air purifiers, avoiding crowded settings, having an isolation/testing protocol before seeing others and sharing air, staying up to date on vaccinations, and using other protective measures such as nasal sprays and mouthwash.

Collaborators were given the option to be named and identified in the final report multiple times throughout the data collection process—in the initial consent form and two post-session confidentiality forms (see [Appendix A](#)) given after the one-on-one interview and the final co-design session. Collaborators were asked throughout the project what data they did not want to be included in the final report, including a final say in the references and quotes used. Collaborators who did not want their name and identity attached to the research are given pseudonyms in the *Findings* and *Discussion* sections to protect their anonymity.

Collaborators were compensated \$35 cash via e-transfer for each session they attended—a total of \$140 cash if the interview and all three co-design workshops were attended.

## Data Collection

### Semi-structured interviews

To begin the research, collaborators were invited for a one-hour semi-structured interview held over Microsoft Teams. All interviews were audio recorded and transcribed for analysis. To improve accessibility and increase collaborators' power in the interview process, they were given the list of proposed questions in the discussion guide ahead of the interview, though they were asked to guide the conversation and talk about what was most pertinent to them. The interviews covered three main topic areas: their general experiences throughout the pandemic as someone still taking COVID-19 precautions, their experience with online communities related to COVID-19, and areas of improvement for inclusivity, harm reduction, or further connectedness within these online communities. See [Appendix B](#) for the full discussion guide.

### Co-design

The second part of the study involved three group co-design workshops with the same collaborators interviewed. The goals of the co-design workshops were to collectively identify a small, actionable need within the community that collaborators wanted to work towards and begin co-creating to address that need with the diverse lived experience and knowledge amongst the group.

Co-design workshops were held virtually over Microsoft Teams and using the digital whiteboarding tool Miro for effective participation and collaboration. For each of the three co-design workshops, two separate time options were made available for collaborators to join the best time that worked for them. Each session lasted between one and two hours. 8 collaborators joined the first workshop, 9 joined the second workshop, and 8 joined the third workshop.

In the first session, collaborators were asked to introduce themselves and get to know one another and to begin ideating areas of improvement they would like to see within their community. Collaborators spent time silently writing down their response to the question “What would you like to see improved in COVID-cautious (CC) online communities?” The remaining time, each collaborator shared what they had written down and the group responded with their thoughts. They would put symbols or emojis next to ideas they agreed with.

The second session was spent reviewing and discussing the commonalities, themes, and connections between ideas that collaborators shared in the first session. Collaborators shared their perspectives, personal experiences, and stories related to challenges they’ve encountered in the themes identified and engaged in discussion to build upon or challenge one another’s thinking.

In the third and final session, collaborators engaged in an activity modified from Purpose-to-Practice (Liberating Structures, n.d.). Collaborators spent a couple minutes writing down their responses to 5 questions related to their purpose and importance of their work in their community, what principles are rules must be in place to achieve their purpose, who must be included in achieving their purpose, how they must organize to achieve their purpose, and the actions and practices they will do. Each collaborator shared a takeaway or something of significant importance they gained from the activity, prompting further discussion.

## Analysis

The analytical frameworks used to guide analysis of the information collected reflect my epistemological perspective as a subjectivist and belief that knowledge is co-created between the researcher and people with lived experience (Moon and Blackman, 2017). In such, I utilize constructivist grounded theory (CGT), which “recognizes that the researcher plays an active and vital role first using in the research process,” as well as reflexive thematic analysis (RTA) which allows for flexibility in the emergence of new understandings, themes, and findings over time and also emphasizes the subjectivity of the researcher in the data

collection and thematic analysis process (Braun & Clarke, 2019, p. 589; Given, 2008, p. 376). In addition, I believe in centering individuals' lived experience and stories in qualitative research and storytelling, which led me to also implement interpretive phenomenological analysis (IPA) (Eatough & Smith, 2017, p. 193). While there may be commonalities amongst collaborators involved in the research, each collaborators' experiences, perspectives, and voice are unique. My epistemological view is to highlight and honour each individual and their uniqueness by using verbatim quotes in support of findings and let collaborators' words speak for themselves. In doing so, collaborators were given the opportunity to review and edit their quotes and references selected to be included in the paper and to represent themselves, their stories, and their words how they want.

Interview transcripts were coded individually using a combination of in vivo codes (direct quotes from collaborators) and constructed codes (created by the researcher), then another round of analysis to refine, organize, and identify parent codes, topics, and themes (Khandkar, 2009). From this analysis, seven topics and 23 themes were identified and are outlined in Table 2 in the *Findings* section. Notes and observations from the co-design workshops were analyzed and reported separately from the interview transcripts, resulting in four overarching findings directly from the co-design method.

## Positionality

The study design, approach, and interpretation of the data is informed by my positionality as a self-identified member of the community subject to the study. I practice ongoing COVID-19 precautions such as wearing a high-quality respirator everywhere indoors in public, and I am a member of several online communities related to the ongoing COVID-19 pandemic. I also organize with a local mutual aid that provides free masks to anyone in my community (Spade, 2020, p. 11). My identity as a white, queer, cis, able-bodied, middle-class woman also influences my positionality as someone with multiple privileged identities, resources, and power, particularly in the research context. While I do not have a disability, my praxis is grounded in Disability Justice (DJ) and its Ten Principles, namely intersectionality, anti-capitalistic politic, and collective liberation (Berne et al., 2018). Described by Freire (2018),

praxis is “reflection and action upon the world in order to transform it” (p. 51). DJ is social justice and disability rights movement that examines disability and ableism as they relate to intersecting forms of oppression, such as race, class, gender, and sexuality, and is guided by the Ten Principles of Disability Justice created by Sins Invalid (Berne et al., 2018).

## Findings

From the interviews, topics and themes were identified related to both collaborators’ personal lived experiences during the pandemic outside of online communities, their experiences within online communities, and what they would like to see improved within these communities, which are outlined in Table 2. Notes and observations from the co-design workshops were analyzed into separate findings. A combination of collaborators’ real names and pseudonyms are included in the findings depending on each collaborators’ desire to be named or to remain anonymous.

**Table 2:** *Summary of topics and themes for each topic*

Topic	Themes
<a href="#">Motivations to keep taking precautions</a>	<a href="#">Health and science</a> <a href="#">Values and beliefs</a>
<a href="#">Lived experiences and challenges</a>	<a href="#">Physical/social isolation and relational impacts</a> <a href="#">Career, financial, medical, lifestyle impacts</a> <a href="#">Psychological isolation and grief</a> <a href="#">Intersectional experiences</a> <a href="#">From isolation to empowerment and community</a>

<u>Types of online communities</u>	<u>Large groups</u>  <u>Smaller group chats and sub-communities</u>
<u>Benefits of online communities</u>	<u>Resource and knowledge sharing</u>  <u>Solidarity and emotional support</u>  <u>Connections and sense of community</u>
<u>What is community?</u>	<u>Shared values, goals, and experiences</u>  <u>Safety and acceptance</u>  <u>Care and support</u>
<u>Conflict, harm, and exclusion within communities</u>	<u>Defensiveness and inability to handle conflict</u>  <u>Strict rules and administration</u>  <u>Lack of intersectional awareness</u>  <u>Centering of certain identities over others</u>
<u>Community needs and reducing intracommunity harm</u>	<u>Addressing defensiveness, managing conflict, and effective communication strategies</u>  <u>Co-creating community decisions and guidelines</u>  <u>Improving intersectional awareness and intracommunity education</u>  <u>Becoming more collective</u>
<u>Co-design results</u>	<u>Collective goals</u>  <u>Intercommunity relations and advocacy</u>  <u>Purpose-to-practice</u>  <u>Relationship and community building through co-design</u>

## Motivations to keep taking precautions

Collaborators' reasons and motivations to continue taking COVID-19 precautions, such as masking, in 2025 when they are no longer required by public health can be distilled to two main reasonings: to keep themselves healthy and to keep others healthy. These reasons are backed by both scientific explanations as well as collaborators' own values and beliefs.

### Health and science

Collaborators showed much more awareness and knowledge on the possible short-term and long-term effects of COVID-19 than the average person. People still taking precautions are more likely to be staying up to date with the science and research related to COVID-19, how it transmits, and its effects on the body, and they do not want to take the chances of those possible outcomes. As Pia says: "I know too much about COVID and post-COVID sequelae, and I'm just not willing to play Russian roulette with my health."

Most collaborators also have personal experiences with disability and chronic illness, either being disabled and/or immunocompromised themselves or having a close loved one who is disabled and/or immunocompromised. They are aware that being infected with COVID-19 could make their existing condition(s) much worse or possibly result in death, even with vaccination. Three collaborators also have personal experience with Long COVID, which dramatically impacted not only their physical health, but mental and emotional health from isolation and a new level of disability unimaginable. Sage and Cam both explained how difficult it is to understand what Long COVID is like until you experience it yourself. Sage dealt with Long COVID for about a year and half, describing it as "traumatic" and having "constant chest pain, and back pain, joint pain." "I was also getting sick all the time," she says, "It really cannot be understated enough how, like, just debilitating it was."

### Values and beliefs

Collaborators' knowledge of COVID-19 intertwines with their values, ethics, and personal beliefs of not doing harm to others. They are aware what contracting and transmitting

COVID-19 can possibly do to someone else's life, and they want to eliminate that possibility as much as they can. Many stated something similar to what Carey says: "I don't wanna, like, kill or disable people. I don't wanna participate in systems that think that it's OK to kill or disable people." They would not feel aligned with their values and beliefs of caring and keeping others and their community safe if they did not also do what they could to prevent the spread of COVID-19 and other diseases.

## Lived experiences and challenges

All collaborators have endured a profound level of isolation, loss, and grief in many different facets of life throughout the past five years solely due to continuing their pandemic precautions. Choosing to mask and limit social interactions have impacted important relationships, jobs and ability to work, and the intense mental and emotional effects from these challenges.

## Physical/social isolation and relational impacts

All collaborators discussed the impact the pandemic and their continuing precautions has had on their relationships and overall ability to interact with others. Most collaborators described straining relationships with family, with some losing all contact with family members. Family members do not understand or take the time to understand their ongoing precautions, and collaborators described being continuously guilted, questioned, and even abused by them. Sage's family is nearly entirely anti-mask and anti-vaccine and said: "Some of them are just so extreme and also just very abusive in the sense of, like, trying to get you to drop precautions or like honestly, just purposely trying to get you sick." Collaborators have had to cut contact with some family members or others in life to keep themselves safe. Jordan explains: "Sometimes it's me withdrawing to protect myself. Sometimes it's just being told 'I don't want to hear from you 'cause this is uncomfortable for me,' is what I'm translating it to." Jordan also described his difficult situation of sharing custody of his child with his mother who is "on total opposite pages on the pandemic and our son's safety," which has caused legal actions to fight for COVID precautions for his son, along with "a lot of emotional

energy.” Jordan’s situation is not uncommon for many parents with opposing views on COVID-19, and there are specific online communities for people who are still taking precautions when family is not to help navigate many similar types of situations.

Loss of friends, partners, and community is another major factor to the isolation collaborators have experienced. Some collaborators have had to end friendships and relationships due to the major difference in values when seeing friends maskless when they were actively showing symptoms or recently exposed to COVID-19. Some have had friends lie to them about their exposures and safety. Many collaborators have slowly lost friendships over time due to the inability to safely see friends in person, only seeing them outdoors in warm weather. This impact has made collaborators question who their real friends are and change their standards for friendships, as Carey says: “People in my inner circle now are sort of living in like that parallel reality sometimes, and that makes it hard to have the same kind of relationships that I used to have with them because, you know, like I’m not super interested in being friends with people who are cool with letting other people get sick or die or possibly be disabled.” Finding new connections, friends, and community with people who still take precautions, both online and in person, is much more natural and has become crucial in helping collaborators deal with the isolation and loss. “It’s become such a, unfortunately, dominant part of my life that I just feel like I click more, you know, I have more in common with people who I don’t have to explain this to,” Pia says.

### Career, financial, medical, lifestyle impacts

Many collaborators have unfortunately experienced huge negative impacts on their lives over the last few years in terms of ability to work, financial challenges, loss of opportunities, delays to get medical care, and an overall change in the ways they live their day-to-day lives. Several collaborators, specifically those who are chronically disabled, mentioned the positive impacts the beginning of the pandemic had in terms of moving work and school remotely. Amina describes what remote work allowed her:

“Before remote work, commuting was a huge barrier for me because of not only the inconsistency of the TTC, but also how far away I was living in Scarborough and working/going to school downtown. It would be exhausting for anyone but having fatigue, chronic illness and chronic pain, the round trip 3 hours of transit would leave me drained and sore.

With the introduction of remote work, all of that disappeared. I didn’t have to mentally and physically prepare myself for such a strenuous route, and then spend hours after coming home recovering. Remote work not only took away the stress of commuting, it also allowed me to be financially stable. For the first time in my life, I could hold a full-time job because I didn’t have to schedule work around medical appointments, a cause of tension, reluctance, and outright hostility from co-workers and bosses alike.

Since all my work was virtual, I was able to attend medical appointments without my workplace knowing/penalizing me, because I wasn’t physically in the office, and I handed in my work on time. The structure of remote work also allowed me grace on flare up days. Previously, if I woke up with a migraine, muscle and nerve pain, extreme fatigue, etc., I’d have to call in sick, which was often. This led to my (presumably) non-disabled coworkers and supervisors seeing me as lazy, and uncaring. With remote work, I can wake up feeling terrible, take some medication, lay down for a bit, and then start my tasks at a later time, with my office being none the wiser.

I am a hyperbolic person by nature but, I am in no way shape or form exaggerating when I say remote work changed my life. It allowed me accessibility, financial stability and a pathway to working in the industry I’ve spent a majority of my life dedicated to.”

Faelix has several disabilities and describes the positive impact remote work had on their quality of work with the ability to maintain overstimulation and using spoon theory, a

metaphor created by Christine Miserandino for disabled people to describe the amount of physical or mental energy they have at any given moment (2003):

“It was easier to not have to deal with the safety-risks, overstimulation, and unpredictability of travel... I could better accommodate myself and work more comfortably... and in not having to hide my symptoms for the comfort of others, I could allocate more spoons to being present with my work.”

The shift back to work in-person and in-office mandates in the last few years has made several collaborators turn down or lose work opportunities because of the lack of safety and inaccessibility of in-person work. Amina worked in theatre and described having to give up goals:

“The first summer after mask mandates were dropped, I felt a deep sense of abandonment and betrayal. From 2022 to now, the complete reversal of any and all COVID safety precautions, has led to me slowly being forced out of my industry. It started off with suggesting folks can come to the office voluntarily twice a week, with masks and testing in place; then it was “encouraged” for folks to come in 3 times a week, this time with no masks or testing, and then requiring that everyone come back to the office full time with no masks, tests, social distancing, air purifiers, etc.

Whether or not leadership of this company were conscious of it, these decisions communicated that anyone who is disabled, chronically ill, immunocompromised, or just cares about not getting and spreading COVID, is not welcome here. As an audience member or staff. I left that company shortly after the implementation of these measures (or lack thereof) only to find that this gross lack of care or consideration, was now the norm across my industry. Every company I interviewed with, every show I went to, every production I worked on, just pretended that COVID is over.

I was now at a crossroads; do I stick through this and try to advocate for better safety measures both for audience members and staff? Or, do I leave theatre altogether,

because there is no company, production or director that cares about COVID? I ended up choosing the latter. It was a heartbreaking decision as I've spent my entire life working towards this, but at the end of the day, I am not going to work for people who are okay with making my already precarious health worse; someone who is okay with further disabling or killing me is not someone I want to work for. I understand the privilege of that statement, not everyone is in a position to pick and choose where they work/who they work for, let alone ensure that the person/company's MO aligns with their morals and ethics."

Most collaborators commented on worsening public health and medical systems in the past few years with the drop of mask mandates in medical facilities. This lack of safety has led many, especially chronically disabled people, to have to delay care. Cam, a non-binary person, had started the process for gender-affirming care in January 2020, but has never been able to go through with it because of their disabilities and risks from COVID exposure being in clinics and hospitals, especially early on when there wasn't a vaccine and later on when mask mandates were dropped. Faelix explains the impact that dropping mask requirements in medical facilities has had on them and the disabled community:

"With masking no longer required in many healthcare settings, people end up having to choose between the risk of contracting a potentially life-threatening COVID infection or foregoing potentially life-saving interventions. And even when we take the risk out of necessity, we often aren't taken seriously. with some doctors even becoming unprofessional due to our masking."

## Psychological isolation and grief

With all these losses and different levels of isolation of course causes many difficult mental and emotional effects for each collaborator. All collaborators hold various types of grief for both their own lives and others—for a world that could have been different. Amina describes a sentiment that many feel:

“I had to grieve losing the life I thought I would live and make everything smaller. My life smaller, my professional aspiration smaller, my person life smaller, and the loneliness and isolation that comes from being someone who takes COVID safety measures. It’s really debilitating.”

For a few, the isolation led to severe depression, emotional breakdowns, and suicidal thoughts and attempts. Several collaborators have grieved loved ones and community members who passed away, either directly from COVID-19, possible long-term effects, or the inability to get the resources and care they need. Collaborators hold a lot of grief in the loss of relationships and community. “I want to find a relationship. I wanted to find love,” one collaborator describes, “I wanted to finally experience a chosen family, which I never got to experience. Now it’s so much harder, like, it’s already hard.”

Collaborators describe their experiences as feeling “gaslit by society,” which is a type of psychological abuse causing the person to question their sanity, or “living in an alternate reality” than everyone else (Huizen, 2024). These feelings come with their own psychological trauma and stress. Being able to form new connections has become much more difficult because of this drastically different experience in realities, as Jordan describes: “It’s a lot of compartmentalization and isolation. I don’t connect with people like I think I would. I’m very superficial in my interactions.” Being the only person wearing a mask in public is isolating, as Haleema, an undergraduate student, says: “It’s very hard for me to have the willpower to put [a mask] on every day. There’s so many days I’m like, OK, I just shouldn’t wear one or it’s like, you know, peer pressure, even though nobody’s actively telling me ‘take it off.’”

Some collaborators also described another type of emotional damage of still having care and concern for loved ones and their community not wanting them to get sick or disabled from COVID-19, even when loved ones and community do not have that same level of care for themselves or towards disabled/COVID-cautious (CC) people. Faelix describes this grief:

“It hurts because whenever someone would get sick, many of us who are disabled, coercively feminized, low income, and/or racialized would find ways

to support them: whether that was getting them masks, tests, groceries/meals, Paxlovid, and other essentials, or disseminating information in accessible formats, or sharing supplements and strategies that research indicated would be helpful to reduce the chances of Long Covid, and so on.

But as the covid denialism spread, those same people who were helped chose ‘back to normal’; many can’t even be bothered to wear a mask around us, even when they know it puts us (and themselves) at risk of severe illness and/or death. How are we supposed to feel about that?”

Collaborators have noticed and thought a lot about how people respond to the information they share about COVID-19 and why most of society has responded by going “back to normal.” Alyson uses social media to share information and science about COVID-19 and discussed the lack of engagement she gets on these posts:

“You likely know that feeling when you’re posting stuff, and there’s some engagement with that. But when it comes to COVID, you just noticed this kind of silence and that was like continuing to happen. Like people weren’t engaging with me. People weren’t talking to me as much, and it started to make me feel crazy.”

While the overall messages from public health and the government play a role on society’s “return to normal” post-vaccine, collaborators shared their theories on why people in their lives continue to ignore the information they share on COVID-19. Some discussed the “logical leaps” people make to reconcile the potential damage they are doing to themselves and others. “They’re capable of understanding it, and on the other hand, it’s very much in their interest to not understand it because it’s kind of, like, a self-protecting thing,” says Carey. Jordan discussed the changed he noticed with colleagues who have stopped masking and taking precautions since their family contracted COVID-19:

“Now you have had it, and your children have gotten it... So how do you reconcile now? I’ve been saying this is really bad, and now I’ve done

something. And now the consequences have landed on my kids, so that doesn't feel good to acknowledge that, right? So then it turns into, 'Well, it's not that bad. I have to tell myself it's not that bad because otherwise it's too uncomfortable to recognize what's just happened and what it could mean long-term for their health.' So it was just like a 180."

Some collaborators discussed the limited capacity of care for vulnerable and disabled people in an ableist and individualistic society, and that able-bodied people don't believe it could happen to them. For collaborators, specifically those who are disabled, there is a lot of grief and feelings of abandonment after witnessing a level of care at the beginning of the pandemic towards vulnerable/disabled people that even inspired a sense of hope in some, but has not been sustained throughout the last several years and caused even more abandonment towards disabled people than there was prior to the pandemic. Faelix explains this abandonment:

"I remember the shift that happened, maybe it was like 2021 or '22. The vaccines came out and we briefly thought things were OK. I still continue to mask. But then they started saying it'll still impact people. But you know, the only people who will die from it are disabled people and the elderly, the people who are already vulnerable. And it's like, do you hate your grandmother? They said the quiet part out loud... 'I don't care 'cause it's just you.' But people don't think it will be them—until it is, and then it's too late."

Several collaborators have also experienced varying degrees of harassment and bullying from masking in public, such as being shoulder-checked, purposely coughed on, and being verbally harassed. Cam describes the bullying they've experienced at school:

"I've had fellow students tell me I should just stay home if I'm so concerned about getting sick at school and tell me, you know, essentially I should give up a degree. Because they don't want to take precautions. I had a lot of bullying at school—both racist and ableist bullying."

## Intersectional experiences

Having one or multiple marginalized identities has affected collaborators' experiences with masking and being COVID-cautious. Several collaborators are queer and discussed how being visibly queer may impact how they are perceived. Avery speaks to this:

“Being visibly queer and masking, I almost feel like this sense of unseriousness about myself. Where if I was a cisman or something and I was masking, people would take it more seriously. But because people can write me off as sort of, ‘Look at this crazy SJW [social justice warrior],’ it’s almost humiliating.”

Race and physical appearance also have an impact on how collaborators have experienced the pandemic. A collaborator who is Indian Muslim commented on how she is used to being “the odd one out” because she wears a hijab. Another collaborator who is Black and Muslim discussed the fact that Black and South Asian communities are the most affected by COVID-19, with the highest number of infections and hospitalizations, and the frustration when seeing her own community not take any precautions and being excluded from community events with the lack of COVID safety measures.

A few collaborators are neurodivergent and discussed how this likely impacts their ongoing COVID-19 precautions and lack of care around following norms related to unmasking after already experiencing similar exclusion. Alyson, who is neurodivergent, comments on this: “Neurotypical people usually really, really need to belong to feel like they can survive. Whereas I think neurodiverse people have been kind of ostracized and isolated already. So maybe that loss isn’t as frightening to us.”

## From isolation to empowerment and community

Some collaborators discussed their personal journeys of struggling with the isolation in the first few years to evolving more into empowerment and less shame in masking within the last couple years. “My fierceness has been increasing, like, I am really not apologetic about it,”

Alyson says, “I know that this is rooted in science and fact and truth, so I’m not gonna act like it’s not. I’m not gonna let people keep normalizing it around me, like, I will not let them live in the space where I am and think that this isn’t happening, ‘cause it is.” A few commented on how learning more about COVID-19 has increased their activism around COVID-19, disability, and justice as a whole and has changed them for the better.

To cope with the isolation, a few collaborators discussed therapy, making art, and having pets to help. However, the most universal way to help with isolation amongst collaborators was through meeting others and finding more community who also still mask and take precautions—both in-person and online.

## Types of online communities

With the isolation, grief, and exclusion that CC individuals experience, a need to connect with others experiencing the same realities arose. Collaborators discussed the various types of online communities they have joined and been a part of to seek information and connection with other people who still take COVID-19 precautions.

### Large groups

Most collaborators are a part of a few Facebook groups related to the ongoing pandemic. There are city and location-based online communities for people who still take COVID-19 precautions and live in the area. These tend to be larger groups, with hundreds to thousands of members depending on the size of the area, open to anyone who takes varying levels of COVID-19 precautions (typically with the minimal of masking indoors), moderated by a few admins, and tend to have written rules on how things are handled within the group. There are other Facebook groups collaborators are in for certain subgroups, such as for parents and identities (e.g., BIPOC and Muslim-specific), or on certain topics, such as for navigating situations when family isn’t taking precautions.

Several collaborators also brought up Twitter/X as a primary community they have found with other CC individuals, though there is no official group or moderation, but rather following

and interacting with one another. Twitter has been a primary way people found more organized groups to join.

Other communities mentioned were within the Meetup app, where individuals attend both online and in-person events, as well as an app developed within the past year specifically for people who take COVID-19 precautions still.

Larger groups can provide diversity for more opinions, as well as typically more responses. As Pia says: “The more people you have, the more momentum and energy there is.”

### Smaller group chats and sub-communities

In addition to the larger groups, many collaborators have joined smaller group chats and communities taking place on Instagram, Twitter, WhatsApp, and Signal. These group chats were usually formed as collaborators sought a need for more personal connections, sometimes for specific identities or topics that they could not get within the larger communities. Some find larger groups to be intimidating and prefer to lurk in these groups, whereas they feel more comfortable and are more active in smaller online groups. “I prefer local groups where I get to know them. Some have become my friends,” Cam says, “I think it’s easier to build that support relationally when it’s a smaller number of people, you get to know each person individually.” Several collaborators also mentioned mutual aid groups they have started or joined that communicate primarily online within group chat. According to Dean Spade (2020), “mutual aid is collective coordination to meet each other’s needs, usually from an awareness that the systems we have in place are not going to meet them” (p. 11). These mutual aid groups are COVID-19 related, some are called mask blocs, which provide high-quality masks to their community for free, as well other tools and information about COVID-19 (MaskBloc.org, n.d.). Other types of mutual aid groups lend air purifiers for events to clean the air.

Pia created and moderated her own smaller location-based Facebook group “with more of a foundation in solidarity” and a difference in how things are run because of her disagreement in moderation in a larger location-based group.

## Benefits of online communities

Collaborators went to social media and online spaces to find updated COVID-19 information and resources, share stories and get emotional support, and find new connections, friendships, and community.

## Resource and knowledge sharing

One of the primary reasons and benefits collaborators expressed from joining online communities for people who still take COVID precautions is the resource and information/knowledge sharing that happens within the communities. This is one of the reasons some collaborators stay in the larger or city-specific groups—because they want access to location-specific and wider-breadth of information shared. With new COVID-related studies, mitigations, and treatments constantly coming out, collaborators find online communities to be the most helpful at staying-up-to date on the latest news and best practices. It also helps them learn about where they can find resources in their area, like vaccination sites, COVID-19 tests, businesses who mask, and sales on masks.

A few collaborators spoke about the important role Twitter has played for them in learning more about COVID-19 and appropriate precautions—Sage being one of them:

“Twitter has saved my life 10 times over. I am so, so, so grateful for Twitter. It taught me everything. I have a master doc of studies that I’ve gotten off Twitter and there are, I think, 350 of them... Like I have learned so, so, so much from Twitter—like, life-saving information. Before I got on Twitter, I did not know the value of an N95 mask... I didn’t have the same level of understanding that I do now.”

Online communities have helped some collaborators get access to practical resources and material support they need, as well. Haleema self-identifies as low-income and talked about an instance when community members sent her masks to sample:

“A bunch of group members sent samples in the mail... They collected them and just like, the way it was done was like, ‘Oh, OK, you know, this is what community is.’ It was just really nice that it was done in a way that I didn’t have to look. I didn’t have to buy a bunch through all these different retailers.”

The mutual aid groups that collaborators are a part of have also been key in finding and sharing practical resources and material support. When Cam was facing a housing crisis, other members in their mutual aid offered them places to stay, gave them rides, and fundraised for them.

### Solidarity and emotional support

An important benefit and reason for collaborators to have joined these online communities was to find solidarity and know that there are thousands of others sharing a similar reality. “It does help you feel less alone...” Jordan says, “It’s just psychologically kind of having some affirmation feeling like other people understand... And that is a big deal. It’s just feeling understood.”

Holding space for people to grieve and vent and feel understood is incredibly important for individuals enduring a lot of psychological isolation and conflict in their personal lives. Collaborators discussed how they have either observed, commented on, or posted themselves needing to vent about a difficult situation in their life relating to their precautions, such as when partners disagree, have shared custody with their kids, or must navigate certain family or work situations. A couple of collaborators have also joined video Zoom calls specifically for CC people from around the world to meet and grieve together. Amina spoke about a virtual group grief group she had joined:

“It was really cathartic... It’s just folks from all over the world being, like, ‘Yeah, I’ve had to give up my lifelong professional goals, my school goals, my social life. I’ve lost so many friends and family members that I don’t speak to.’ And it’s just this sense of, like, commiserating together about something that we’re all experiencing at the same time.”

For those who have Long COVID or have had lost people to COVID-19, they have also found solidarity and support in online spaces to be incredibly helpful in their healing and grief. Sage shared how much others sharing their stories have helped her:

“Some people are very open online, or even just reading news articles and stuff about people who have Long COVID. For me, that was really transformational, and it made me feel a lot less alone too, because it really humanizes it... Also, especially hearing horror stories about COVID, like people who end up in the ICU or people who die. Yeah, it really makes it feel real. And I lost a family member to COVID back in 2022. So it’s kind of like that solidarity feeling in hearing other people who have also lost people to COVID.”

## Connections and sense of community

Several collaborators have made friends and found community within the various online spaces for CC individuals and have found that to have been incredibly beneficial for their mental health and coping with isolation. Alyson shared her story of a monumental loss she experienced in her personal life and with a group of friends but was able to rebuild connections online. “I have made many more authentic loving connections online since then,” she says, “I’ve been really grateful to find those connections, most of them are online.” Several collaborators have been able to meet with these connections and new friends in person as well.

As mentioned previously, a few collaborators have started or joined mutual aid groups and not only have found organizing for COVID-19 precautions as helping with their feelings of

despair, but finding community with like-minded individuals and working towards something together is another major benefit. Avery talked about a very important connection she made when organizing her mutual aid group:

“Meeting the person who I cofounded the [mutual aid group] with was just amazing... We literally bonded, like, we clicked just like that. And we were immediately ready to go; immediately ready to put so much effort and energy into what we wanted to do. And then also being able to like hold space for each other to air out, like you know, this happened this week and stuff like that before we would have like a meeting and actually act on that exact thing that we were frustrated about. And I think that that's just been very, very special.”

Cam had a similar experience starting their mask bloc:

“Mainly it's been with the mask bloc—we mostly connect online to coordinate and to be in touch with each other. And that's been honestly lifesaving for me because I was feeling a lot of despair. And then, my friend approached me saying, ‘Hey, why don't we just do something about this?’ And that gave us a lot of hope and connected me with more people. I was facing a lot of ostracization and a lot of isolation, so it made me connected and made me realize a lot more people cared.”

## What is community?

Collaborators were asked to define what community means to them in their own words, and some went on to explain what is *not* community.

### Shared values, goals, and experiences

One key element of community that collaborators discussed was having collectively shared values, goals, and experiences amongst everyone. Some collaborators said that community must have one core thing in common and is believed strongly in—in this case, it's continuing

COVID-19 precautions. Other collaborators went further to define that they don't feel in community with everyone who shares the same one thing in common—there must be a set of values and beliefs that are held true amongst everyone in order to feel in community. “Coming together and deciding ‘These are our values. These are the lines that we’re gonna hold and, like, really committing to holding that line,’” Carey said. Sage touches on a level of solidarity that’s needed to be in community:

“I don’t that just ‘cause we’re doing the same action that we’re necessarily in community. I think there has to be a level of intersectional solidarity. There’s a lot of rich, white COVID-cautious people who are just doing this to protect their own health—who don’t give a fuck about anybody else in the community.”

For some, community does not necessarily mean having a shared identity either. “I think it can be helpful as a tool to say we have a shared identity and therefore we might have similarities. I’m not discounting that,” says Cam, “Solidarity is important of course. But for more practical purposes, I think I wouldn’t rely on it.” Amina and other collaborators also don’t tend to identify with being in the “COVID-cautious (CC) community”:

“I’d say I’m part of the COVID-cautious community in the same way that most people do their taxes: begrudgingly. As in, I’m technically part of this, but I would prefer to define myself as someone who practices Disability Justice. If to choose between the two terms, I would call myself COVID-cautious if someone asked, but I would more likely call myself... disability advocate.”

## Safety and acceptance

Collaborators also brought up safety and acceptance being vital to be in community with others. A few collaborators discussed about how not only physical safety is important, but emotional safety is just as much, as Haleema speaks to: “I could feel physically safe with a

lot of people in these groups, but what about emotionally? Seems like I don't know if I can always confidently say that."

Collaborators also discussed an ideal community where everyone is welcome and accepted as they are. While it is nice to consider others within a community as friends, a few collaborators said this isn't always realistic and you don't have to be friends with or even like people you are in community with. Ideally, everyone is welcome and accepted, as long as they are safe to be around. Pia speaks to her ideal community:

"You want somebody to feel like they can be part of that community, no matter how down and out they are, no matter if they're not friends with a single person there and don't know anybody there, they should be welcome with open arms if possible. That's my ideal version, but I don't know if that works out that way in real life."

## Care and support

Another pillar that some collaborators find necessary in community is a level of internal care and support—people that are reliable to help one another. Cam phrases this by saying: "It's more helpful to ask the question of 'Who can be there for you when you need help?'" This is reflected in the way that community members provide resources, education and information, and material support for one another. Sage mentioned an anecdote of community care she experienced recently:

"Recently, I had strep throat, and so my COVID-cautious friend went and got antibiotics for me. And then this week she and her partner had COVID, and so I went over and tested them with a PlusLife so they can go get Paxlovid. So things like that where you're taking care of each other is a big part of it."

A few collaborators reflected on their experiences of feeling abandoned by other former communities they were apart of before the pandemic due to their lack of precautions. "Community is the capacity to see each other as human and not disposable," Faelix says.

“Community is not abandoning the most marginalized and vulnerable members of your demographic and refusing to take simple actions to protect and safeguard not just them, but yourself,” Amina says.

## Conflict, harm, and exclusion within communities

While collaborators overall have had positive experiences within their online communities and interactions, most have witnessed or been a part of conflict, and some of experienced harm or exclusion within their communities.

### Defensiveness and inability to handle conflict

Conflict and disagreements are inevitable, as many collaborators attested to. It’s the ways in which conflict is handled where issues arise. Collaborators talked about situations of conflict and disagreement in their online communities where those involved would become reactive, defensive, or personally attack others with rude or disrespectful comments or behaviour. This can result in a conflict escalating and harm or exclusion being done, sometimes resulting in the removal of members from a community. “I feel like there’s a spectrum of causing harm, right?” Sage says, “Like you can cause harm and take accountability, or you can cause harm, and then refuse to take accountability and drag it on and on and on.” Ways in which conflict and harm is handled can result in further harm to all parties. Some collaborators spoke of this “cancel culture” when someone makes a mistake, they are shamed and removed from a community rather than being given grace and creating a learning opportunity for everyone. Alyson spoke of a difficult incident in a group chat she created that lead to the entire group chat turning against her and her leaving without being given much explanation why. “I noticed that there was a lot of shame-based conversation in the responses and that to me, long-term, is not going to work in our community. I think we should move past shame and try to have these productive conversations where someone isn’t feeling like shit because of a learning moment” she says. Conflict and discourse are not always harmful when handled well and can actually be community building and educational, as Sage speaks to:

“I find it really frustrating when people say that the COVID-cautious community in-fights all the time ‘cause I think having discourse is a way to establish values and figure out who we align ourselves with and what demographics and groups we want to be prioritizing and stuff like that.”

Collaborators acknowledged the impact that nearly 5 years of isolation has on the community and how they may handle situations. Avery spoke to this: “People are at their wit’s end. It’s not a fundamentally healthy community because we’re so ostracized and because so many of us have been directly harmed, right?” Collective trauma and grief can play a large role in people’s responses getting defensive, and Cam tries to be graceful knowing this: “We’ve undergone a collective trauma... And how people respond to that trauma, I can’t blame anyone for being defensive. No one is hyperprivileged at all, except for a very select few. Everyone is dealing with something to a degree, so I’ll try to be empathetic to that.” When there is infighting within a community, it can lead to less organizing needed and people not being able to get resources they need, as Faelix speaks to: “It’s hard ‘cause people are fighting amongst themselves. And I mean that makes sense—I think that is by design because if we’re busying fighting each other over scraps it’s hard to create a resistance. It’s harder to organize things like food shares or community gardens and such.”

### Strict rules and administration

In more formal, often larger groups, there are rules and admins to moderate who is accepted to a group and when conflict or disrespect does occur. While rules and moderation may help provide a sense of safety for community members, they do not guarantee safety, especially when rules are not collectively agreed upon among members. Collaborators spoke of their issues with rules being strict, specifically regarding what can and cannot be discussed within a community. In one location-based group that multiple collaborators are or have been a member of, every post must be approved by admins and there are rules asking members to be apolitical, with one of the rules being “We amplify but do not advocate.” One of the largest points of division regarding this rule and for people within the group is regarding the genocide in Palestine. Haleema spoke about a time she wanted to make a post mentioning Palestine

within the group and was rejected because “We’re meant to take a neutral and apolitical stand.” A Muslim friend of Haleema was also banned from the same group. “[The admins’] reasoning behind it... It was basically, ‘You’re talking too much about these other issues... when it’s not exactly needed... It’s not even like she left because she felt unsafe. She was just banned from that group.” This community member was someone who provided a lot of resources, and Haleema says: “I feel like they were always pouring a lot into the community and then to just be banned. I know they were very disappointed... It is sad they were sort of cut from a main group that has a lot of resources.”

However, the rules are not always necessarily followed in other circumstances and instead adhere to what admins are comfortable with, as Haleema describes: “I do know certain political issues have been discussed in the past and even after my comments were rejected and that friend I mentioned was banned.” Jordan shared an even more explicit blanket rule in a Zoom chat he joined that met every Sunday: “Cannot discuss Israel/Palestine because it was too heated, and people were on opposite sides of it.” These kinds of restrictions on what can and cannot be discussed within a group don’t apply to groups for intersectional minorities or smaller group chats. “That’s not the case for the Black Indigenous people of colour [group] and even the Muslim one, and these small group chats, it’s not the case at all,” Haleema says.

Pia, who is an admin of a smaller CC community Facebook group, takes a different approach to the moderation of her group and rules:

“It’s very laissez faire. With the other group they pre-approve all posts, and with my group, I welcome you to post just like that. Most people can have like a back and forth without me reading through everything or like worrying about if I’m not there to moderate things if things get out of hand. ‘Cause I definitely wanted a different vibe from the other group.”

Pia just uses the pre-suggested rules from Facebook but provides more of the “larger vibe of the group” in the description, specifically regarding the lack of moderation and being respectful of one another.

### Lack of intersectional awareness

One major critique from collaborators is the lack of intersectional awareness and discussions within some of the community. By this, collaborators mean other non-COVID struggles, their relations to COVID as an issue, and effects on people within and outside the CC community. Most collaborators hold the position that struggles are connected, and the issue of COVID should not be discussed in isolation. Thus, specific topics should not be completely banned within a community discussion, as Carey speaks to:

“I know that people try to keep things focused on COVID, which I get, but also everything is connected to everything else. You can’t just like remove an ongoing genocide that’s also been facilitated by lack of medical and all that stuff. You can’t like ‘Oh, well, that’s a separate issue. We don’t talk about that here.’”

There is divisiveness within CC online spaces specifically on the Israel-Palestine conflict of land occupation and political Zionism, which became more prevalent in mainstream media and societal awareness following the events of October 7, 2023 (Uras et al., 2023). All collaborators see being CC directly tied to values of justice and equity, so they find it shocking and frustrating when others do not make the same connections. “These spaces where we’re COVID-cautious feel like it’s so tied to justice and disability. It’s just so surprising to me that it’s controversial to be opposed to this genocide,” says Jordan.

Lack of knowledge of Disability Justice (DJ), ableism, and classism are also issues collaborators have found within CC online spaces. The solely individualistic reasons why some community members take precautions is very difficult for several collaborators to reason with, as Avery describes: “There’s this huge split in the community between eugenics

and Disability Justice and one side of the people who are in online spaces are like, ‘I’m doing this because I’m better and everyone’s zombie-brained...’ It’s just frustrating.” Some even feel unsafe and choose not to be in certain spaces due to this lack of alignment and exclusion that occurs. Amina speaks to why she is not very active in many CC communities, specifically larger location-based ones:

There’s an online community located in my city that’s been a helpful resource for finding COVID-safe practitioners/businesses, as well as sourcing PPE. However, it’s also a space with a lot of affluent white folks who are not necessarily connected to Disability Justice. So, they’re COVID-conscious, but they also can be ableist at the same time, so it’s a difficult space to be in. Before joining, I had acquaintances as well as people in my personal life give me a heads up about the group and the behaviour/actions that go on. The main disclaimer that I’ve gotten is about the rampant Zionism in that community which, regarding my identity, my religion, my culture, my ethnicity—that’s not a safe space for me to be in... I find that the COVID-cautious community online is not one that I gravitate towards, unless I know that there’s Disability Justice implemented, that there’s a large BIPOC presence, and the politics of that community align with myself in terms of things like anti-Zionism.”

Several collaborators spoke about a controversial division among those in CC communities related to classism and more privileged, affluent community members using their surplus on expensive air-cleaning devices, such as UV lamps and air purifiers, for their own extracurricular activities like indoor dining and promoting the use of them in these groups. “Not everyone can afford a several hundreds of dollars device that you have to keep yourself safe... That’s very dangerous advice,” Amina says, “Do not encourage people to do indoor dining unmasked, especially in a group that is allegedly COVID-conscious.” Sage also spoke about this conflict on Twitter, which resulted in one person creating a list doxxing marginalized community members who opposed a UV lamp brand: “It really does divide people based on more privileged people who have access to UV and want to use it, quote,

‘Go back to normal,’ versus people who cannot afford UV and also don’t fully trust UV as a fix or an end-all, be-all solution.” Collaborators expressed frustration with the individualism and lack of resource sharing and mutual aid from more affluent members. It can be difficult to ask for resources in these groups where there is such a class divide. Cam spoke to the harm they’ve experienced in CC communities when they bring up access to wealth, and less harm they’ve experienced in other non-COVID-specific mutual aid groups:

“I’ve encountered a greater level of harm in the wider groups, over the smaller things, too. I would just tell a white woman like, ‘Hey, maybe you should consider the reason you can stay at home and isolate and so on is because you’ve got access to wealth...’ There’s less of class divide in the mutual aid groups I was previously in because those are the folks who already were needing help and providing help and already connected... Majority of us who are active in that group are living under the poverty line. It was easier for me to ask to receive help because I was with folks who understood what it’s like to be living on \$11,000 a year.”

Due to this lack of intersectional awareness and feelings of exclusion and unsafety, sub-communities have needed to be created specifically for BIPOC, queer, anti-Zionist, disabled, or young community members to have the discourse on these intersectional struggles. Alyson has been able to find safety in these sub-communities for some of her identities:

“A lot of people I have connected with also have either depression or CPTSD. So also finding that kind of sub-community within COVID safeness was a really vital part in me feeling safe as well, ‘cause a lot of them understand what it’s like to have been neglected and bullied and ostracized and isolated and left out. So that just made me a lot more safe, just being able to communicate with people that already get that.”

Collaborator Pia speaks to why she created her sub-community: “In its intention, it’s trying to make connections between different forms of oppression, and how those struggles are connected, and so it’s being very deliberately political. And it’s not a space to express support or solidarity for Israelis at this time... I think the more spaces there are the better.” Cam talked about being in many different sub-communities due to all their intersectional identities and various organizing efforts they are a part of: “I kind of hop in and out of many groups. There’s not really one defined community for me.”

### Centering of certain identities over others

The last major challenge that collaborators brought into focus was the issue with which voices were being the most prioritized in CC online communities. Amina speaks to one example of this in terms of race:

“A lot of it will be white folks talking over people who have less privilege and access... Like a Black person posting a photo of themselves, like a selfie, and they’re wearing a blue surgical mask. And someone in the comments, usually white, will disparage them or make a snarky comment about how it should or a KN95 or it should be an N95 or something like that. As if there’s not obvious cost barriers based on race that would cause that person to maybe not be able to access KN95s.”

Collaborators have found that CC online spaces tend to skew more white, and BIPOC collaborators have noted that they have sometimes been the only person of colour in an online space due to many systemic and societal barriers. “Racialized folks, we just deal with so much more, and we had to drop off, even though we didn’t want to,” Cam said. Carey also spoke about how the mask bloc they organize with is predominantly white: “It’s hard because I can see like a lot of the communities of colour are super marginalized. So they probably don’t have the time or resources, but at the same time that means that their voices are not properly represented, and that’s a challenge.” When marginalized people are in a space, they are often the ones doing a lot of the work in terms of educating others on justice

and calling out inequity, but this can come with many consequences, such as draining their energy and possibly being further excluded within a community. Sage speaks to this:

“I think a lot of that work tends to fall on the more vulnerable and marginalized people in our community, ‘cause they are usually the ones who spot it first, but they’re just the ones who recognize it and call it out. So I think then they take a lot of flak and push back from people and get further kind of marginalized within the COVID-cautious community.”

Some collaborators also discussed the need to prioritize other groups in terms of organizing who to provide access to masks, air purifiers, and other types of precautions. Sage says: “I think where we as a community can improve the most is prioritizing the most vulnerable. I think we’re huge in missing things like prisons and hospitals and childcare and elderly care.”

However, a couple of collaborators spoke of instances in their online communities where conflict occurred between them and someone with multiple marginalized identities. These situations were difficult to navigate and caused them a lot of stress because several community members sided with the multiply marginalized member. These collaborators mentioned how these conflicts turned into more personal attacks rather than constructive criticism and did not find it just by the way people immediately sided with the more marginalized person. “This is dated... activism. We do not need to listen to the most oppressed person in the room. We listen to the most radical person in the room,” Alyson says regarding her own conflict, which resulted in her having to leave the community and lose several friends. Relatedly, conflict occurs when there are conflicting access needs and community members are unsure how to prioritize all groups, as Cam talked about in relation to organizing COVID-cautious (CC) events.

“What happens when people disagree about what exactly is or isn’t COVID-cautious enough for an event? Do we prioritize outreach to folks who aren’t in a place to mask at the moment? Or, you know, making sure the event is mask mandatory to ensure that people who are immunocompromised are safer.

Like, how does hybrid work when we have limited technology and so on?  
There's so many conflicting access needs."

## Community needs and reducing intracommunity harm

The challenges and conflicts within these online communities are complex, inevitable and do not have any one solution. However, collaborators discussed both new ideas and methods they have found effective in addressing these challenges and conflicts. They also discussed needs and things they would like to see more within the community.

### Addressing defensiveness, managing conflict, and effective communication strategies

Collaborators had several ideas on ways to improve communication and difficult conflicts within communities. First, simply bringing awareness to ineffective communication and why defensiveness may be occurring could help mitigate further harm being caused. Jordan brought up the idea of "A message in the group saying, 'This is a traumatic time for everybody, and we absolutely encourage you to all be gentle and respect each other, but if somebody is disrespectful to you... remind yourself they're lashing out. Probably something is going on with them. And we should all try to be less defensive in that way.'" Pia, a community admin, brought up the need to do "call-ins" rather than "callouts": "If you have a concern with my behaviour or anybody else's, that's 100% valid, but let's talk about what the behaviour is that bothered you. Let's not go into personal attack mode or callout mode."

Some collaborators brought up the idea of having more community members, perhaps those with more interpersonal conflict management experience, volunteer and take turns having designated roles to help mediate and maintain a community discussion or overall environment. Cam brought up the idea of a "designated vibes checker" for community members to volunteer at different times and "notice it's feeling tense" and "point out vibes." Faelix also brought up the idea of having mediators, "people who can self soothe, are trained in de-escalation" and possibly have more resources they can point people towards.

A longer, but important component in improving communities is building trust between community members, a couple collaborators mentioned. Once trust is established, harm is less likely to occur in the first place, and people are more understanding of intentions when conflicts or faults do occur. However, trust can usually only be built and earned from several interpersonal interactions over a long period of time, which are not likely to occur in larger communities where these types of interactions do not typically take place.

### Co-creating community decisions and guidelines

Another method of possibly reducing intracommunity exclusion and harm is diminishing or dissolving hierarchy within communities and only having a select one or few people, making decisions, creating group rules, and moderating group discussions. A couple collaborators spoke of how decisions and guidelines within communities could be more co-created amongst members. For example, admin Pia has implemented this approach to an extent in the community she runs: “Whenever there’s an important decision to be made in that group, I ask a question and I do a poll, and that way the decision is gonna basically be made by everybody who wants to participate in that particular decision.” Cam thought of the idea of posing questions to be answered collectively by community members to help co-create community guidelines:

“The guidelines are just nothing, really, unless they're made together 'cause otherwise you're just telling someone else what to do, right? Like that's it. It doesn't work right and it has to be like an organic thing... How I would create guidelines, honestly, would be to have a bunch of discussions. Like, what would you like to see? What does care look like for you? What does care look like for the wider community? How do you like to best be cared for? What are access needs that we have individually? How would we like access need conflicts to be handled? What does someone listening to you look like, right? Because we can say, listen to others. But what does that actually look like?”

## Improving intersectional awareness and intracommunity education

Increasing intersectional solidarity amongst the community will not happen overnight, but collaborators proposed a few ideas to educate more of the community on areas related to justice, equity, and intersectional issues to help reduce instances of ableism, racism, classism, Zionism, and other forms of harm. Jordan and Amina both proposed required learnings when you first join an online community before being accepted, such as a one-hour workshop that new members must watch regarding equity. Amina proposed the Sins Invalid Disability Justice 101 course, which sends you a set of educational documents and learnings for three days in a row to get a foundation of DJ:

“I think having a baseline of Disability Justice before being allowed access to online COVID-conscious spaces will make COVID-conscious spaces not only more tolerable but also, much more effective; in the sense of community building, educating and organizing.”

However, mistakes and even harm are still bound to happen despite initial education efforts. A couple of collaborators pointed out it's how both other community members and the person who commits the mistake/harm respond and can turn it into an educational opportunity for everyone. Sage talked about an example where someone took accountability and apologized for their mistake, rather than getting defensive:

“This account that I follow, they posted calling the unknown disease in Congo ‘the Congo disease’ and people rightfully called them out for being racist, and they immediately took the post down and put out an apology... And it hasn't been brought up since, right? So, like, it's not that hard. I mean, it is hard to take accountability, but it's doable.”

Similarly, how community members respond to mistakes without using shame-based language can instead turn into learning opportunities, as Faelix describes:

“The only way that we're gonna survive is if we can extend each other some grace and accept people as imperfect works in progress; they aren't always gonna have right language or politics. Sometimes there'll be conflict and messiness—and yes, it is frustrating, but so long as there is an acknowledgment of each other's humanity and inherent lack of disposability, there is a foundation to build on.

All of us have likely learned something thanks to someone else extending us patience and education—these are opportunities (for those with capacity) to pay it forward.”

### Becoming more collective

Collaborators also talked about a lack of unity and collectiveness within the CC community—working towards something together as one. Some commented on a need within the community to do more to establish values, fundamental principles, and what issues should be focused on. Some collaborators discussed how they have observed many individuals and groups within the community working separately towards somewhat different (but still similar overall) issues with dispersed efforts. Avery speaks to what she would like to see more within the community regarding this:

“I would love more than anything else to collectivize the efforts that people are doing in the city. I think that fracturing is a really harmful thing that happens to a lot of leftist movements or community-based movements. And I've talked a lot about this with two other COVID organizers in Toronto about some sort of webpage where people can pull resources or something similar to that that wouldn't be subject to DDoS [Distributed Denial-of-Service] attacks. Something like that where it's like, you can find all of the information here. You don't have to search and search and search for it. You have recent studies here. You have social groups here. You have where to rent filters and where to

get masks... And then like, ‘How do I get involved? How do I get organized? Why should I care?’”

Haleema discussed a concern she has with the community in focusing more on “non-issues” or government issues rather than more collective, on-the-ground organizing.

“We definitely need to be working on non-government strategies. Don’t get me wrong, I think one area I think is a good way to advocate to them is clean air. That makes sense because that’s a very systemic thing... But for example, with masks, you can dispense those pretty much anywhere. That can be a community thing, but clean air can’t... I feel sometimes there’s a lot of attention given to things that are just, to me, a non-issue. Are we really trying to figure out the best patio spots when I feel there’s more serious issues we could be addressing?”

The reasons behind why people are taking COVID precautions still is divisive among the community, and some collaborators thus have noticed an inconsistency in principles and people’s practices due to their underlying motivations—for example, taking off one’s mask indoors when speaking at a conference. Sage discussed her desire to see more alignment in the community around resistance and the more systemic issues she ties to the pandemic:

“I think as a community, we should be pushing for militancy and resisting going back to normal. Even if we do get sterilizing vaccines, I would never take my mask off again... I think we kind of need to decide how to handle the people who are more privileged, who are more just in it for themselves.”

Lastly, Faelix, who has organized worked in anti-oppression, inclusion, and community organizing, spoke about the need for transformative justice in community spaces. According to Mingus (2022), transformative justice (TJ) is an abolitionist, political framework created by and for oppressed communities that seeks to responding to violence, harm and abuse “without creating more violence and/or engaging in harm reduction to lessen the violence”

(p. 17). TJ centers community-building, support, healing, and skill-building and decenters relying on the state for needs, specifically in addressing violence.

## Co-design results

The three co-design workshops revealed how synchronous, organized workshops not only help community members identify and organize shared principles and goals for the community to work towards but also allow for more cooperative real-time discourse and help build interpersonal relationships and trust that cannot occur in solely asynchronous and/or hierarchical online community models.

## Collective goals

Through both individual reflection and group discussion, collective goals on what collaborators would like to work towards and see improved within the COVID-cautious (CC) community were identified.

### *Reducing intracommunity harm / education on intersectional issues*

A key theme discovered in the interviews, collaborators again brought up the need to reduce the ableism, racism, Zionism, xenophobia, classism, etc. they have witnessed in their online communities and promote/educate more cross-solidarity movements and intersectional issues outside of just COVID-19. Collaborators want more political discussions and for communities to work within existing Disability Justice (DJ) frameworks. As part of this topic, issues and concerns were brought up around those within the community who are resistant to expanding their views or becoming more educated on these topics.

### *Intracommunity communication and conflict management*

Relatedly, improving how community members communicate with one another to be a safer space to make mistakes was another topic area re-introduced from the interviews. Collaborators want to see more reminders or group guidelines on calling in versus calling

out, using less shame-based communication, and self-reflecting before responding with defensiveness. In addition, developing more internal conflict processes, especially in relation to safety and how to handle potential bad actors who may do more harm than is reconcilable.

### *Where to focus organizing efforts*

Collaborators also are focused on how they can help more marginalized communities through activism and organizing. Specifically, collaborators mentioned creating safe spaces for children and elders and more outreach and safety materials for people on the streets and in segregated institutions (e.g., prisons, long-term care, hospitals, schools, in-patient treatment, shelters, community centers).

### *Building support networks and work distribution*

In addition, collaborators are more interested in building more community support offline/in-person. They see a need to increase how mutual aid functions within and outside of CC communities and the networks to support each other. They want to see more privileged community members get more involved and contribute, money, resources, time, transportation, etc. to those who do not have access to supplies and resources they need to keep themselves safe. Distributing more work to privileged and able-bodied community members would allow for more sustainability and less burnout for disabled community members. Connection with existing mutual aid support networks would also help with this, which is expanded on in the [Intercommunity relations and advocacy](#) section.

### *Educational and art-based organizing/outreach to non-COVID-cautious people*

Lastly, a heavy topic of conversation was information dissemination—how to inform more people about COVID-19 and influence more people to take precautions again. Many ideas on how to reach people were discussed: art-based propaganda, storytelling and making those most impacted visible, science communication, and modelling. More connections with other external communities/mutual aid groups also could expand influence, as

discussed in [Intercommunity relations and advocacy](#). Amina suggested the resource [How to Talk to Your Loved Ones About Covid](#) (2024).

The use of shame rhetoric to influence people to mask was a controversial topic amongst collaborators. Some see shame as an appropriate tactic to get to people's emotions and make them want to do the right thing if they are aware of the harm they cause. Other collaborators, however, noted that they have not seen shame work in their own experiences in attempting to get others to mask, and people's responses to shame may be to get defensive, resent/offend the accuser, or simply ignore the harm they are causing. "While shaming can feel righteous, it should not be used as a replacement for education," one collaborator noted. Those against shame-based tactics discussed how the person using shame may also be susceptible to feeling a form of elitism and feel that they are better than the person they are shaming, which could be a detriment in their own reflection and complicity on other forms of oppression.

### [Intercommunity relations and advocacy](#)

An area of interest that was discussed among collaborators was the need for more relations outside of the CC community to 1) model precautions to others, 2) educate them on COVID-19 and precautions, 3) influence precaution-taking, and 4) expand networks to increase longevity of support and mutual aid within and beyond the community. Collaborators acknowledged the gaps in mutual aid support and general lack of knowledge on mutual aid and interconnecting issues within the CC community. They see one way to help their own community as well as others is by amplifying and embedding into more established mutual aid groups and to bring COVID-19 safety and DJ principles into them. This would hopefully lead to more support, expand, and strengthen mutual aid and the necessary networks for those who are COVID-cautious.

At the same time, the intracommunity work should be done in parallel to create a more supportive and warm community for new people to feel welcomed and encouraged to take precautions again. Allowing space and time for people to get educated instead of assuming

perfectionism upfront would be necessary in creating this type of environment, collaborators say.

### Purpose-to-practice

Within the interviews and first co-design workshop, some collaborators brought up a need for more clarity of goals, norms, and values that a community holds. Online communities are often created without these established or input from all its members. The final activity collaborators participated in was to help them better tie their overall purpose and what they find important to themselves and their larger community to the actions they take within their community, how they currently or want to organize themselves, who they currently or want to involve in their efforts, and what principles they believe should be followed. Individual responses to each of the activity prompts can be found in [Appendix C](#). This activity showed how a community with many different goals and norms can better align their overall purpose and find more direction on how they can organize themselves. This activity demonstrated just the beginning of a possible approach to how online communities can create more inclusive environments with aligned purposes, principles, and structure that allow all members to be valued and heard into how a community is run.

### Relationship and community building through co-design

While it was not a goal of the co-design method, one large outcome was the relationship and community building that occurred amongst collaborators. Sharing this same “identity” of being COVID-cautious (CC) and the many similar experiences and challenges that come with it, there was a quick development of camaraderie and a sense of trust just within the first session. When each collaborator gave an introduction of themselves and their reasons for and experiences with still taking COVID precautions, other collaborators expressed empathy and care for each other and the challenges they’ve faced. Since many collaborators have very few or nobody else in their day-to-day lives who live in this shared reality, they were eager to connect with each other on this topic. One collaborator commented in the chat that it’s “very validating to be around like-minded people.” While sessions were only scheduled

for an hour, many collaborators voluntarily chose to continue longer than the hour because they were engaged in the discussions and wanted to continue.

Collaborators actively listened to each other with interest, building upon each other's points and ideas. Many expressed gratitude in learning from each other and the many resources that were shared verbally. While disagreement did occur between collaborators, the dialogue remained respectful and focused on hearing each other's perspectives and reasonings rather than getting defensive, attacking, or any conflict or arguments occurring. Collaborators seemed comfortable stating their differing opinions and that they would be treated with respect.

A few collaborators were even asked to be connected with each other outside of the study to continue their discussions and relationship building. One collaborator said that they would miss the group and expressed hope to meet everyone in person at some point.

## Discussion

By working with a new community that has experienced a unique kind of physical, social, and psychological isolation due to their COVID-19 precautions for the ongoing pandemic, I explored how online spaces have emerged for this community to cope with their isolation and share knowledge and resources with one another, provide emotional support and solidarity, and find new connections with people who have shared experiences. These findings on the benefits of online communities for people in who still take COVID-19 pandemic precautions align with previous studies' findings on benefits of other online communities, specifically for chronic-illness and disease-specific related support groups (Allen et al., 2016). However, from this research, not only were stories and anecdotes shared to highlight the importance and specific nuances of these benefits for members of these CC communities, but they displayed an important need for those within the CC community: to bridge the online communities with offline/in-person community for support and further connection. In the theme of resource and information sharing, the types of knowledge shared within communities were not only disease or management-specific in terms of

sharing science and new developments/studies, but often practical and location-specific resources for people to access offline (e.g., vaccination sites, where to find COVID-19 tests, businesses who mask, etc.). In addition, there is evidence of offline material support that results from these online spaces, such as sharing and exchanging masks, testing devices, and other types of mutual aid, like collaborator Cam receiving rides and places to stay from trusted community members. CC communities should encourage and explore further ways for more community members, particularly privileged members, to learn and engage with mutual aid principles and existing mutual aid networks to expand the access to life-saving material support (Spade, 2020).

All collaborators discussed losing important connections they had with people in their lives pre-pandemic, whether it be friends, family, or community members. There is substantial evidence that social connection is human physiological need, in the same category as other basic needs like oxygen, water, food, and shelter (Bauer et al., 2025). The need for social connection and to fill those profound losses and make new connections with people living in their same reality is crucial for collaborators' mental health and wellness. With such a small number of the general population living in this reality, it is near impossible for CC individuals to find these new connections solely offline. Most collaborators described some of the connections they made with others online often resulting in or at least seeking some form of face-to-face or offline/in-person connection to help fulfill this need. These findings show that while the emotional support and solidarity that collaborators gained from their online communities is cathartic and helpful for their coping, these online support systems still do not replace the need for human-to-human interaction.

However, when conflict and harm occur in these online communities, that can cut people off from these material resources and offline connections, while they are already being excluded and isolated in many other parts of their life from simply taking COVID-19 precautions. The potential impact of this intracommunity harm and exclusion within these types of marginalized communities and specifically towards individuals with multiple marginalized, intersectional identities can be even more consequential and possibly even

life-threatening. In addition, divisiveness, infighting, and fracturing in communities leads to less ability to organize and resist systemic oppression as one collective, as collaborators explained.

The online disinhibition effect can explain at least partly why conflict and harm are more likely to occur in online communities rather than offline (Suler, 2004). Asynchronous communication and the absence of face-to-face cues may lead to misinterpretations of posts, comments, or messages and a higher likelihood of reactive or defensive responses rather than considering those on the receiving end, their contexts, and the potential impacts. However, the online disinhibition effect does not nullify intentional harm or exclusion that still occurs within these communities where individuals are personally attacked or subjected to ableism, racism, sexism, homophobia, etc. Nor does it fully discount members' lack of education and ignorance around intersectional issues, inability to handle intracommunity conflict, or unwillingness to take accountability for harm caused.

For CC communities to become more inclusive environments and a collective, united movement, those who hold positions of power in these communities, such as admins or well-recognized voices within the community, should consider how their group structure, rules, and themselves as individuals may be contributing to existing societal power dynamics, ableism, and other forms of bias and prejudice (Gray, 2012; Miller, 2017; Walker & DeVito, 2020). These admins and notable community members should reflect on exclusion or harm that has occurred within these communities, whose voices are being prioritized, what are the needs and goals of more marginalized community members, and what is lacking to meet these needs and goals. Admins can consider utilizing asynchronous feedback and participatory mechanisms such as surveys and polls or allowing self-moderation or forms of participatory policymaking in their communities (Bakarat & Redmiles, 2022; Centivany, 2016; Smithson et al., 2011). Diversifying admin teams could also balance societal power dynamics and reduce some forms of bias by having more diverse perspectives (Walker & DeVito, 2020). Lastly, admins should not only work on increasing their own education on intersectional issues, but promoting and creating a space

for community members to share, reflect on, and discuss resources and topics related to intersectional issues, justice, equity, etc.

All community members should also consider reflecting on their own internal values, principles, goals, biases, and the potential impact, harm, or exclusion they may inflict before posting or responding within their online communities. Considering the community member(s) on the other sides of their posts, comments, and messages and their own contexts, identities, individual struggles, as well as the community's collective struggles and traumas could help prevent unintentional harm in online spaces. When unintentional harm does occur, community members should consider a "calling in" educational and informational approach rather than a "calling out" personal attack approach. Once those that inflicted the harm learn why it was harmful, they should highly consider taking accountability with care rather than defensiveness and further escalation.

Synchronous, organized, and facilitated co-design and participatory methods should be considered as a tool to provide community members, specifically marginalized, harmed, and radical community members, a voice in and design of the purpose, principles, guidelines, and processes of their prospective online communities. The findings of this study demonstrate how synchronous, face-to-face (virtual or offline) workshops or meetings can improve communication, alignment, relationship building, and trust for communities that primarily exist in asynchronous online platforms and struggle with divisiveness and conflict management.

It's important to note that synchronous facilitated meetings come with their own challenges and risks of creating harm and exclusion. If an online community has an admin(s), they will likely be initiating and possibly facilitating these sessions. Consider having multiple facilitators/moderators involved to diversify perspectives and co-create session guidelines, format, and processes to minimize likelihood and impact of potential harm. Moderators should consider having and changing designated roles for each session to distribute work and allow for others to moderate, as well as learning facilitation skills beforehand.

## Implications of research

As described throughout, online communities are crucial for the wellbeing of individuals and communities who experience any level of isolation, marginalization, or exclusion. These findings suggest implications for researchers and designers of online platforms that host these organized and organic communities to consider how the identified benefits of online communities can be further supported and emphasized. Learning more about and designing for sub-communities to benefit those with specific intersectional identities should also be explored. More importantly from these findings, researchers and designers should better understand how harm, exclusion, power dynamics, and bias manifest in different ways, and how might the design of community goals, guidelines, rules, processes or lack thereof may contribute to these issues. In addition, findings suggest the importance of synchronous, face-to-face, and offline communication and relational building. Researchers and designers of these platforms should explore how to bridge the gap between the asynchronous/online and the synchronous/offline, especially for those who may have difficulty to connect in-person due to their disability, immunocompromised status, or concern for their health and others in regard to COVID-19.

The findings of this study suggest implications for admins, moderators, and community members of online communities which experience various levels of intracommunity harm and exclusion resulting from conflict to explore use of synchronous structured meetings and co-design activities to establish collective community goals, principles, structure, processes, and actions when conflict or harm does occur. Findings suggest that holding synchronous, face-to-face sessions may not only help better establish the unified purpose and maintenance of an online community but help community members feel more connected with the community, build a sense of trust more quickly, share commonalities and learnings with one another, and create new interpersonal relationships among members.

Lastly, unexpected but notable findings of this study suggest implications for members of the COVID-cautious (CC) community to begin learning or further continue learning about intersectional struggles, Disability Justice (DJ), mutual aid networks and organizing, collectivizing initiatives and resources, and transformative justice (TJ) (Berne et al., 2018; Mingus, 2022; Spade, 2020). Collaborators of this study identified issues they have witnessed within the communities around lack of solidarity amongst more privileged members, centering certain identities and voices of others, lack of resource and material support organizing and sharing, and incidents of classism, ableism, racism, and Zionism creating unsafe environments. The fragmentation created by these issues leads to further isolation for community members already experiencing substantial levels of physical, social, and psychological isolation. This is a call for members of the CC community to reflect on their own biases, lack of knowledge or understanding on the listed topics, and their own contributions to these issues. To begin learning about these topics, see [Appendix D](#) for recommended books and resources shared by Faelix and other collaborators throughout the study.

## Limitations and future research

This study has several limitations due to the nature of qualitative studies being specific to the scope, the collaborators, and its context. The findings of this study are unique to the experiences and thoughts of the collaborators at the time of the sessions and do not reflect the entirety of the CC community, nor do they remain stagnant with the collaborators' evolving viewpoints and experiences on the subjects. With all collaborators residing in Canada, the majority being white, and other gaps present to represent a full spectrum of diversity, conducting further research on specific intersections within the CC community could provide more insight into those intersectional marginalized experiences, such as with low-income Black, disabled experiences or non-Western experiences. Examining how identity-based power dynamics stemming from existing societal structures may play a role within CC online communities should also be looked at in future research (Walker & DeVito, 2020). As proposed, further research is needed to explore the use of

synchronous co-design and participatory methods for online communities to establish community purpose, principles, guidelines, and actions and how conflict and harm can be handled. Future research could include a longitudinal study with one online community to evaluate the usefulness of these methods and observe these conflicts or points of harm first-hand. Observing interactions, frequency and occurrences of conflict and harm, trust and relationship building, and online community citizenship behavior (OCCB) over time following synchronous co-design sessions could help evaluate the usefulness of these methods (Liu et al., 2020). Future research might utilize diverse methods to gather information, such as diary studies, observations, and analysis of posts and interactions within an online community.

## Conclusion

In this study, individuals who still take COVID-19 precautions, such as masking, described their unique lived, intersectional experiences and challenges related to isolation, lifestyle impacts, grief, and their evolving perspectives and empowerments. These research collaborators have all found some sense of relief and different benefits by joining and creating their own online communities with others who “identify” as COVID-cautious (CC), aligning with other studies on online communities. In addition, the findings imply the importance of synchronous and offline communication and connections to expand on these benefits. While beneficial and developed as inclusive spaces, this research describes different forms of conflict, harm, and exclusion that occurs within these online communities. Synchronous co-design workshops were proposed as one possible method to reduce intracommunity harm, identify shared goals, and build trust within CC online communities. These findings offer implications for researchers and designers to further explore how online community platform design decisions can reduce intracommunity harm, and for online community admins and members to examine their individual and collective contributions in how to address the identified issues and community needs.

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# Appendices

## Appendix A

### Post-interview confidentiality form

It is my goal and responsibility to use the information that you have shared responsibly. Now that you have completed the interview, I would like to give you the opportunity to provide us with additional feedback on how you prefer to have your data handled. Please check one of the following statements:

\_\_\_ You may share the information just as I provided it. No details need to be changed and you may use my real name when using my data in publications or presentations.

\_\_\_ You may share the information just as I provided it; however, please do not use my real name. I realize that others might identify me based on the data, even though my name will not be used.

\_\_\_ You may share the information I provided; however, please do not use my real name and please change details that might make me identifiable to others. In particular, it is my wish that the following specific pieces of my data not be shared without first altering the data so as to make me unidentifiable (describe this data in the space below):

\_\_\_\_\_

\_\_\_ You may contact me if you have any questions about sharing my data with others. The best way to reach me is (provide phone number or email):

Respondent's signature\_\_\_\_\_ Date\_\_\_\_\_

Investigator's signature\_\_\_\_\_ Date\_\_\_\_\_

## Appendix B

### Semi-structured interview discussion guide

#### *Introductory questions (5 minutes)*

Lead-off question: Can you tell me a bit about yourself? Feel free to introduce yourself in whichever way you would like.

Follow-up/demographic questions:

Part of this research is to understand the unique experiences of people with diverse, marginalized, and intersectional identities. I have a few demographic questions to ask you to get a better sense of how your different identities contribute to your experiences in relation to the pandemic and online communities.

- What is your age?
- What are your pronouns?
- Please describe your race/ethnicity.
- Do you identify as 2SLGBTQIA+? Feel free to specify further if you'd like.
- Do you have a disability or are of immunocompromised status? Feel free to specify further if you'd like.

#### *Topic domain: Experiences throughout the pandemic (15 minutes)*

Lead-off question: Tell me about what your experience has been like throughout the pandemic, specifically in the last 2 years as the rest of the world has “moved on.”

Follow-up questions (in no particular order):

- Tell me about any isolation you have experienced being someone who still takes COVID precautions.
  - Tell me about how this has affected you, mentally, emotionally, and physically?
  - Are there things have you helped you cope with this isolation?

- Are there others in your life who also practice precautions, and you can be safe around?
- What motivates you to continue practicing precautions?
- [If has a marginalized identity] Tell me about how your identity as [blank] has affected your experience throughout this pandemic.
- Is there anything else you would like to mention regarding your experience throughout the pandemic?

*Topic domain: Experiences with online communities (15 minutes)*

Lead-off question: Next I would like to talk about your experience in the online communities you are a part of for people who still take COVID precautions. As a reminder, please refrain from recalling names of community members who can be identified without their consent. You said that you were a part of [insert online communities indicated in interest form]. Tell me about how you learned about these online communities and what made you interested in joining them.

Follow-up questions:

- How long have you been a part of this/these communities?
- Have you been a part of any other online communities before this/these communities? If so, tell me briefly about them.
  - Have you noticed any difference between the COVID-conscious community and these other online communities?
- Tell me a bit more about your engagement with this community.
  - For observers: Is there any reason you haven't interacted with posts or other members? What keeps you in the community?
  - For contributors: How has your interaction been with others within the community? Please share any specific interactions that you can recall if you are comfortable.

- Tell me about some of the ways being a member of this online community has helped you throughout the pandemic. Feel free to share any specific interactions that were of benefit that come to mind.
- In your words, what does community mean to you? How do you know when you are in community with others?
  - How would you define this specifically for the COVID-conscious community?

For group admins:

- Tell me about how you became an admin of this community.
- Are there other admins? How do you work with them? Do you have different roles?
- Tell me about some of the guidelines or policies you have implemented.
- How were they decided upon? Was there anything or situation that prompted these guidelines?
  - How often are guidelines reviewed and updated?
  - If there are no guidelines, why not?
- Tell me about one or two difficult situations that occurred within the community and how it was handled
- Is there any way you have engaged with community members to improve guidelines/policies/rules?

*Topic domain: Areas of improvement for inclusivity and connectedness in online communities (15 minutes)*

Lead-off question: Now I want to discuss ways in which this/these online communities can be improved. From your experience, is there anything you have witnessed or been involved in yourself that has been exclusive or caused marginalization or harm within the community?

Follow-up questions:

- Tell me about a specific situation, if any come to mind and you are comfortable.

- How did the exclusion or harm transpire?
- How was the situation handled by group admins, if at all?
- How did the situation make you feel? Did you do anything as a result of it (e.g., leave the group)?
- What are ways in which you would like to see more inclusion within the COVID-conscious community? What areas are most pressing to be addressed within this community?
  - What ideas do you have to foster more connectedness and joy within the community?

## Appendix C

### Co-design workshop purpose-to-practice activity raw responses

Purpose: Why is the work important to you and the larger community?
dreaming and putting into practice better futures
fighting eugenics
our collective survival and liberation are bound up in each others'
Stay alive so we can fight
Wanting to build a better future - need to be alive to do that!!!!
Community care
Prevent death and suffering
Aligning with do no harm and harm reduction and not causing excess harm to others
disabled people are worth it
A better future is possible!!!
Protecting individual + community health
adapting to needs in organizing spaces brings in more people and helps us be flexible
we have to stay alive to see the revolution ^_^
Antiracism, antisexism, anti transphobia, anti xenophobia, anti eugenics, anti ableism, anti zionism, etc
We need to keep our communities as healthy as possible!
We all deserve the right to breathe clean indoor air!
To combat isolation; community is where healing and resource building happens. Isolation can be a death sentence to disabled people.
We have obligations/responsibilities to one another - especially those who have less agency and more years left - our children
reducing unnecessary suffering and deaths

future generations need us to do this work
--

Principle: What rules must we absolutely obey to succeed in achieving our purpose?
Abandoning harmful power structures and hierarchy
Harm reduction
change is constant - how we adapt to it matters
inform new and old people of existing best practices in organizing, group culture, and DJ
Aligning with core values
leadership of the most impacted (and everyone can be impacted in different ways)
Remaining steadfast and militant; this is a life or death fight
Prioritizing the most vulnerable and at risk
navigating access needs (& access needs conflicts) with care and compassion
relationship building is key, the world we're fighting for is cold
Accountability
Ensuring that all individuals are included
balancing transparency with security
Nothing about us without us - always listen to disabled people
not reinventing the wheel, the tools are out there to help your group sustain itself
Not recreating harmful & punitive systems and uneven power dynamics / hierarchies
loving and respecting ourselves so we can better love and respect others
do no harm/take no shit
"We Keep Us Safe" means we keep us safe. There is a duty to take care of each other
remaining open and vulnerable
I don't like rules!
Nobody is Disposable. Nobody Left Behind
It is never too late to adopt better practices. Everyone is still learning
I would focus on principles e.g. mutual respect, social justice, etc.
science and ethics before ego/comfort/convenience

Participants: Who can contribute to achieving our purpose and must be included?
Disabled people!
Children, elderly, prisoners, institutionalized, marginalized, poor people, BIPOC
different aspects of involvement are possible according to access needs & security concerns
Everyone who aligns with our values and goals
people both inside and outside of "CC communities"
everyone "left" of the bad faith right wing
Everyone can contribute in their own way

this is a sustained crisis and is enabled by barrier-less spread, we need to learn what our community's boundaries are but not be precious about it
learn from disaster and other disability groups
identifying who in our communities can do this work!
Informed medical professionals and scientists; people tend to respect their opinions
People who stopped masking and started again. (help "convert" non-maskers)
Everyone can contribute in various ways, at different times. There is room for everyone
poor and unhoused people, children, everybody else
People with stories about why they mask; relatable emotions are compelling (ie: wanting to protect their kids/loved ones/partner)
teach-ins; scientists/medical professionals educating others/ informing uninformed people on class solidarity and how the government is sacrificing people for profit. Remind them of their oath to do no harm, then show them how to do less harm.
Activists/ Leftist + activism communities. (because why havent we as queers learned from the AIDs crisis???)
favour inclusivity and play to strengths - don't need to be inclusive to bad faith actors
Unions members -- especially teachers and nurses
Environmentalists need to hop aboard the clean air wagon!
People with both visible and invisible disabilities; unfortunately people need to be reminded that we are actual people, much like them. (The government said sacrificing disabled and vulnerable people was acceptable- make them requesting that stance_
'-- Public Education Symposium focus on community care >> speakers could include epidemiologists (education/to discuss current state of the pandemic), medical professionals (education/to explain how it can impact the body) Panel to of people who have long covid and/or have lost people to covid (to show the risk) covid-safer employers (to show it is possible/provide how-to's), Covid safer event organizers (to show it is possible/provide how-to's) >> Community care strategizing groups '
*Advocates/witnesses For patients, kids in school, tenants, etc- anyone who is needing to advocate for safety precautions. Show institutions that their harm is witnessed and will be combatted. Remove the ease of putting people in danger.

Structure: How must we organize (both macro- and microstructures) and distribute ourselves/resources to achieve our purpose?
Non Hierarchical
Prioritizing safety and security and accessibility
With recognizing that informal imbalances can and do exist regardless of type of internal structure - having organic and continuous conversations to realign balances
Both online and in-person ways of interacting
Accountability when this does occur and remedying the harm
Without recreating the harmful power structures we've been taught
Discovering points of unity together

Crip time, inclusive, accessible, welcoming, sustainable
Flexible structures that can evolve if/when needed
remembering why we are doing this work and who is asking us to do it
Being aware of the different amount of time everyone has - not everyone has the same 24 hours
evolving and flexible, warm and forgiving, accountable and safe (in so many ways!)
Strategic outreach to people at risk of being radicalized by right-wing propaganda; elders, those in rural communities, those who subscribe to "alternative health"
Form covid-safe(r) disability caucuses in every union local
multi-layer /level approach.
neighbourhood groups
Flexibility and redundancy in organisation - group versus solo efforts
lateral organisation versus vertical
graffiti/posters
collaborate with existing organizations/events to show people that precautions are possible.
Community centers/ Community hubs
Grass Roots organizations
School Campuses

Practices: What are we going to do? What will we offer to our community members and how will we do it?
Masks! :D
Tests, clean air, etc
Education, resources, information
healing space and time
Grief support
Providing education that meets the needs of different types of learners
Propaganda; fight the information war
Safe spaces (physical and online)
Honouring and remembering the dead
Translation and interpretation into multiple languages & formats (incl. plain language, ASL)
re-distributive and mutual access to expensive infrastructure (masks, hepa/hvac, tests, cleaning solution)
deciding what education looks like in our context
Keep showing up; being visible helps people not forget that "different"/Safer is possible
Insist on more virtual options for participation
Fighting for employer paid sick days - 2 weeks total at minimum
speaking up when covid minimization or misinformation happens
community, solidarity, rationality, informational support, instrumental support, advocacy
challenge institutions

## Appendix D

### Recommended books and resources shared by collaborators

#### *COVID-19, Disability Justice, & Mutual Aid*

- *Care Work: Dreaming Disability Justice* by Leah Lakshmi Piepzna-Samarasinha
- *Mutual Aid: Building Solidarity During This Crisis (And the Next)* by Dean Spade
- *The Care Manifesto: The Politics of Interdependence* by The Care Collective
- *Let This Radicalize You: Organizing and the Revolution of Reciprocal Care* by Kelly Hayes & Mariame Kaba
- *The Future is Disabled: Prophecies, Love Notes & Mourning Songs* by Leah Lakshmi Piepzna-Samarasinha
- *Medical Gaslighting: How to Get the Care You Deserve Within a System that Makes You Fight for Your Life* by Ilana Jacqueline
- *Disability Visibility: First Person Stories from the Twenty-First Century* edited by Alice Wong
- *Feminist Queer Crip* by Alison Kafer
- *The Viral Underclass: The Human Toll When Inequality and Disease Collide* by Steven W. Thrasher
- *We Want Them Infected: How the Failed Quest for Herd Immunity Led Doctors to Embrace the Anti-Vaccine Movement and Blinded Americans to the Threat of COVID* by Jonathan Howard
- *When the Body Says No: The Cost of Hidden Stress* by Gabor Maté, MD
- [Sins Invalid Crip Crash Course](#)
- [#PowerToLive Coalition](#)
  - Living document: [Survival for Folks Who Need #PowerToLive During a Power Shut Off](#)
- [OK Doomer blog](#) by Jessica Wildfire
- [How to Talk to Your Loved Ones About Covid document](#)

### *Feminized Labour & Considerations*

- *Emotional Labour: The Invisible Work Shaping Our Lives and How to Claim our Power* by Rose Hackman
- *Invisible Women: Data Bias in a World Designed for Men* by Caroline Criado Perez

### *Mental Health & Shame Work*

#### Shame:

- *Unlearning Shame: How we can Reject Self-Blame Culture and Reclaim Our Power* by Devon Price, PhD

#### Anger:

- *Love and Rage: The Path of Liberation Through Anger* by Lama Rod Owens

#### Dissociation:

- *Dissociation Made Simple: A Stigma Free Guide to Embracing Your Dissociate Mind and Navigating Daily Life* by Jamie Marich, PhD
- *No Bad Parts: Healing Trauma & Restoring Wholeness with the Internal Family Systems Model* by Richard C Schwartz, PhD, forward by Alanis Morissette
- *Introduction to Internal Family Systems (Second Edition)* by Richard C Schwartz, PhD

#### PTSD/CPTSD:

- *The Pain We Carry: Healing from Complex CPTSD for People of Colour* by Natalie Y Gutierrez, LMFT, forward by Jennifer Mullay, PSYD
- *The Complex PTSD Workbook: A Mind-Body Approach to Regaining Emotional Control & Becoming Whole* by Arielle Schwartz, PhD

#### Boundaries:

- *Unf\*ck Your Boundaries: Build Better Relationships Through Consent, Communication, and Expressing Your Needs* by Faith G Harper, PhD, LPC-S, ACS, ACN

### *Revolution & Harm Reduction*

- *The Revolution Will Not be Funded: Beyond the Non-Profit Industrial Complex* by INCITE!
- *Saving our Own Lives: A Liberatory Practice of Harm Reduction* by Shira Hassan, with forwards by adrienne maree brown & afterword by Rosario Dawson (page 117 talks about recovery readiness, risk reduction, and public health-based harm reduction)
- *The Will to Change: Men, Masculinity and Love* by bell hooks
- *Where We Stand: Class Matters* by bell hooks
- *Liberated to the Bone: Histories. Bodies. Futures.* by Susan Raffo

### *Combatting Cancel Culture & Transformative Justice*

- *Emergent Strategy: Shaping Change, Changing Worlds* by adrienne maree brown
- *Holding Change: The Way of Emergent Strategy Facilitation and Mediation* by adrienne maree brown
- *We Will Not Cancel Us: And Other Dreams of Transformative Justice* by adrienne maree brown
- *Beyond Survival: Strategies and Stories from the Transformative Justice Movement* edited by Ejeris Dixon & Leah Lakshmi Piepzna-Samarasinha
- *We Do This 'Til We Free Us: Abolitionist Organizing and Transforming Justice* by Mariama Kaba
- *Turn This World Inside Out: The Emergence of Nurturance Culture* by Nora Samaran
- *Loving Corrections* by adrienne maree brown
- *Practicing New Worlds: Abolition and Emergent Strategies* by Andrea J. Ritchie
- *Conflict is Not Abuse: Overstating Harm, Community Responsibility and the Duty of Repair* by Sarah Schulman

### *Accountability (Workbooks)*

- *On Repentance and Repair: Making Amends in an Unapologetic World* by Danya Ruttenberg

- *Fumbling Towards Repair: A Workbook for Community Accountability Facilitators* by Mariame Kaba & Shira Hassan
- *Creative Interventions Toolkit: A Practical Guide to Stop Interpersonal Violence* by Creative Interventions
- *How to Be Accountable Workbook: Take Responsibility to Change Your Behaviour, Boundaries & Relationships* by Joe Biel, & Faith G Harper, PhD, LPC-S, ACS, ACN