Research recruitment and consent methods in a pandemic: A qualitative study of COVID-19 patients' perspectives

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Introduction

Virtual data collection methods and consent procedures adopted in response to the COVID-19 pandemic enabled continued research activities, but also introduced concerns about equity, inclusivity, representation, and privacy. Recent studies [1-3] have explored these issues from institutional and researcher perspectives, but there is a need to explore patient perspectives and preferences.

Objective

To investigate patients' perspectives on the recruitment and consent process for COVID-19 research studies.

Methods

Study design & participants

We conducted an exploratory qualitative focus group and interview study**.** Participants were 16 British Columbians (23-78 years old) who self-identified as having had COVID-19 recruited through personal contacts, social media, and REACH BC, an online platform that connects British Columbians to health research opportunities. Most of the participants were women, early pandemic survivors, and reported having education or previous experiences in research.

Semi-structured focus groups and interviews

As informed by a discussion guide developed by the research team, we asked participants to discuss recruitment and consent methods and factors influencing their willingness to participate in COVID-19 research. We audio recorded all sessions, which a research assistant transcribed verbatim.

Data analysis

Two analysts independently coded the transcripts inductively using NVivo and developed thematic summaries of each coding.

Results

Table 1. Summary of key findings and sample quotes

Theme	Sub-themes & sample quotes
Autonomy and flexibility of participation	**Decision of when and how to participate** " I do want to retain the right. … I want the - the choice to be mine, not implied." (Participant 15)
	Control data "making it clear that you are always in control is very important to – to lessen that sense of burden." (participant 9)
	Time and frequency "…as long as our time is respected, my time is respected. As long as I know what I'm getting into at the start of it, then I don't feel like it's terribly burdensome." (Participant 7)
	Recovery stage and health status "…I think it does matter where somebody is in their recovery, and we're all in different places…it's really unpredictable for a lot of us." (Participant 4)
Attitude toward research on COVID-19	**Interest in research** "…just to know that people are using my data could be very validating for some of us…it would help with that feeling of being counted in some way." (Participant 4)
	Altruism "you know with something as new as this, you also want to help too. I think it's your civic duty…to help out and try to get through this." (Participant 12)
Privacy concerns and protections	**Misuse** "I think my main hesitation with [research on my records] would be if it was tied to more personal information about me, or more of my medical history." (Participant 13)
	De-identification "As long as it's anonymous I don't care, 'cause I know how much work it is to get the data…" (Participant 3)
Remote, virtual approaches are preferred	"Email survey kind of thing would be cool, 'cause then it's a bit more flexible on" (Participant 13) "I guess it depends on the age group. Because if you're thinking about young people, obviously the best way to reach would be to advertise on social media…" (Participant 11)

Conclusions

COVID-19 patients value hearing about research opportunities and want autonomy in deciding whether and how they participate in consent-based research studies. Researchers must be sensitive and considerate toward patient preferences and concerns to promote research participation and engagement. Results should be interpreted with consideration of potential selection bias.

Lessons Learned

- Although participants in this study wanted to hear about COVID-19 related research opportunities, many processes for doing so are not equitable or inclusive.
- In BC, decision-makers insisted that patients needed to consent to be contacted for COVID-19 studies either by agreeing during telephone follow up or signing up on a website in advance to avoid patients receiving multiple calls. This systematically excludes those who mistrust the health system and marginalized and vulnerable patient groups who may have low health literacy or little access to research information and information technology, and/or cognitive impairment.
- Health authorities should reassess these processes to improve access, equity and inclusivity by encouraging healthcare professionals to notify all patients of consent-based research opportunities without the requirement for multiple-step consent processes.

References

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