RAPID REVIEW OF THE COORDINATION OF THE PROVINCIAL COVID-19 RESEARCH RESPONSE

Successes, challenges, opportunities

FINAL REPORT

May 2021
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1. Executive Summary

Background

Since early 2020, there has been an unprecedented mobilization of COVID-19 research worldwide resulting in an avalanche of studies, methodologies, and results. British Columbia’s health research community has initiated a number of COVID-19-related research projects and initiatives to contribute to the COVID-19 research response in British Columbia (BC), as well as to the national and global COVID-19 research efforts. Early on in the pandemic, the BC research community was encouraged to bring these efforts together, to the extent possible, through a coordinated provincial research response. Elements of the coordinated research response in BC included, but were not limited to:

- The rapid and significant infusion of funding for BC-led research (from a range of national and provincial sources).
- The BC COVID-19 Strategic Research Advisory Committee (SRAC).
- The COVID-19 Clinical Research Coordination Initiative (CRCI).
- The COVID-19 patient cohort, which evolved into the Post-COVID Interdisciplinary Clinical Care Network (PC-ICCN) and the Post-COVID recovery clinics.
- Research competitions tied to BC COVID-19 research priorities (e.g., Michael Smith Foundation for Health Research (MSFHR), Genome BC, MSFHR-Canadian Institutes of Health Research (CIHR) partnership).
- Efforts to strengthen, streamline and/or pivot existing platforms and processes (e.g., Health Data Platform, rapid ethical review for COVID-19 clinical research through Research Ethics BC, rapid data access protocols for COVID-19 research, REACH BC).
- BC Academic Health Science Network (BCAHSN) COVID-19 Research Inventory.
- Facilitation and communication around COVID-19 clinical trials by Clinical Trials BC.

In the Fall of 2020, at the request of the Ministry of Health, MSFHR commissioned an independent, rapid review of the coordination of the COVID-19 research response. The primary purpose of the rapid review was to define and describe what worked, and what did not, in the context of a coordinated provincial research response. Learnings focused on the implementation, outcomes, and gaps in the coordination of the research response, with implications extending beyond the pandemic to highlight opportunities to strengthen coordination across the BC health research system in the future.

The rapid review consisted of thirty-one (31) semi-structured interviews conducted between December 2020 and January 2021, with stakeholders representing a wide range of perspectives, including patient
partners, provincial and regional health system leaders, academic leaders, researchers, funders, shared infrastructure leaders, and research support personnel. The interviews were guided by eight questions developed in consultation with SRAC and published December 2020 in Issue 2 of the BC COVID-19 Strategic Research Framework - and supplemented by a review of documents and websites related to the provincial research response. Therefore, this review does not give a comprehensive accounting of the provincial COVID-19 research response; rather it is a synthesis of the knowledge, understanding and experiences of 31 different stakeholders (at the time of interview) who were involved in the provincial COVID-19 research response, validated where possible by a review of available information. In reading this synthesis, it is important to keep in mind that BC’s provincial research response was not formal – no one organization had responsibility and authority for its implementation and monitoring – rather it took a significant and collegial effort by BC’s research community to collaborate and undertake their work within the context of a larger and broader research response.

Several high-level themes emerged from the rapid review, and these are described in the report. However, detailing the nuances of specific challenges around coordination of data, and to a lesser extent, patient consent, ethics and privacy review and approval, was not possible within the constraints of the rapid review approach.

Key findings

- A key success of the COVID-19 provincial research response is that the coordination is valued by senior decision-makers in the Ministry of Health (MoH) and the Office of the Provincial Health Officer (PHO).

- Other successes included:
  - An “impressive” start to the coordination, with early direction from the PHO, and leadership from BC Centre for Disease Control (BCCDC), MSFHR and the University of British Columbia (UBC), as well as collaboration within the clinical research community.
  - Rapid infusion of significant funding for research in BC to kickstart COVID-19 research.
  - Leveraging of existing infrastructure and partnerships to address BC COVID-19 research priorities.
  - Progress on the Health Data Platform, rapid data access protocols and rapid ethics review for clinical research.

- SRAC was broadly perceived as a useful structure, particularly its role as a conduit between senior researchers and senior decision-makers in the Office of the PHO, and as a respected forum for identifying provincial COVID-19 research priorities. However, the lack of a patient perspective and an equity lens in the early formation of SRAC was seen as a major omission; this was addressed through expanded membership but continued to be an area of concern for some stakeholders.

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5 Appendix D: List of questions that guided the stakeholder interviews
6 Appendix E: List of documents and websites related to the COVID-19 research response
• There was a significant amount of confusion about the purpose, scope, authority, and accountabilities of the different COVID-19 research coordinating initiatives, particularly SRAC and CRCI. Stakeholders observed that this confusion about “who’s in charge of what” reflects similar challenges in the broader research system.

• Overall, much of the coordination within the provincial research response appeared to have been built from existing relationships between well-positioned individuals and institutions. While there was progress in engaging a wider range of institutions and perspectives, including health authorities, the response had yet to achieve an integrated provincial reach.

• The impact of COVID-specific coordination appeared to be limited because of larger, long-standing problems of coordination in the health research system. The review revealed a level of distress in the research community for the lost opportunity for BC’s COVID-19 research response to make more of a difference to the BC population and health system outcomes because of long-standing problems of coordination in the health research system. Some respondents indicated that what may have been accepted as “normal” in the past was not sufficient in the context of a pandemic requiring a rapid research response.

• There was an identified gap in true provincial research capability due to the persistence of health authority-specific operational and ethics reviews and a lack of infrastructure support for health research in and across different health authorities. While there had been some movement of the coordination “needle” between health authorities, for example, increased coordination between health authority research departments, and multi-health authority agreement on COVID-19 rapid clinical research ethics review, this still fell far short of seamless multi-health authority cooperation needed for a robust health research system.

Concluding remarks
While some important steps were made towards the coordination of the provincial COVID-19 research response in BC, which included significant, voluntary and collegial efforts on the part of many individuals and organizations, the rapid review findings revealed that there was not an integrated and sustained provincial research response to the pandemic, a public health emergency. There is an opportunity for the Province to critically reflect on the learnings from this review, and those provided by other provincial initiatives and organizations, to take steps to design a fit-for-purpose, integrated health research system, capable of addressing BC’s current and future health challenges.
2. Project Background

Since early 2020, BC’s health research community has initiated a number of COVID-19-related research and initiatives to contribute to the COVID-19 research response in BC, as well as to the national and global research efforts. Early on in the pandemic, the research community was encouraged to bring these efforts together through a coordinated provincial COVID-19 research response. New supporting elements included rapid research response funds, new coordinating structures and initiatives (including a provincial Strategic Research Advisory Committee – SRAC), processes to accelerate research approval and data access, and knowledge sharing events.

The Ministry of Health (MoH), Michael Smith Foundation for Health Research (MSFHR), BC Academic Health Science Network (BC-AHSN) and SRAC are engaged in ongoing dialogue to determine what further actions are required to strengthen coordination of the COVID-19 provincial research response. At the request of MoH, this independent rapid review was commissioned by MSFHR to define and describe what worked, and what did not, in the context of a provincial research response.

Thirty-one (31) semi-structured interviews were conducted between December 2020 and January 2021, with stakeholders representing a wide range of perspectives. The initial list of interviewees was generated by MSFHR staff in consultation with the SRAC Co-Chairs and senior representatives from MoH and MSFHR. Some interviewees were added to the list in response to gaps in perspective that emerged from the early interviews. The final interview list included senior stakeholders from the Office of the Provincial Health Officer (PHO), MoH, health authorities7, universities, patient safety, and funding organizations. The interviews also included patient partners, shared infrastructure leaders, health authority research office staff, and researchers (both academic and clinician-researchers). The interviews were supplemented by a review of documents and websites related to the research response, including mid-term reports from researchers funded through MSFHR’s COVID-19 Research Response Fund.

This review does not give a comprehensive accounting of the provincial COVID-19 research response; rather it is a synthesis of the knowledge, understanding and experiences of 31 different stakeholders (at the time of interview) who were involved in the provincial COVID-19 research response, validated where possible by a review of available information. It is important to note that the interview set represented just a sample of stakeholders, and some important perspectives may be missing. It is also important to note that BC’s provincial research response was not formal – no one organization had responsibility and authority for its implementation and monitoring – rather it took a significant and collegial effort by BC’s research community to collaborate and undertake their work within the context of a larger and broader research response.

Several high-level themes emerged from the rapid review, and these are described in the report. However, detailing all the nuances around coordination of data, privacy and ethics review and approval, contracts, and consent was neither intended nor possible within the constraints of the rapid review approach.

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7 For the purposes of reporting, senior stakeholders from the PHO, MoH and health authorities are grouped together as “health system leaders”.

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3. Contextualizing the Findings: A Complexity Lens

The initiatives associated with the COVID-19 provincial research response were designed to address immediate challenges in a fast-evolving pandemic environment. However, in the context of an unprecedented public health emergency layered over a fragmented pre-existing health research system, the COVID-19 research response coordination is best conceptualized as a complex adaptive system intervention.

The rapid review revealed several characteristics consistent with a complex system intervention:

- The boundaries of the intervention itself, as well as the system to be influenced, were unclear to stakeholders.
- There were many actors with a legitimate claim to undertake coordination, or aspects of the coordination for the research response. Multiple actors were undertaking coordination initiatives and evolving their actions in response to others’ initiatives.
- There was a high degree of uncertainty among diverse stakeholders about what to do to “fix” coordination of the system in which research and knowledge translation are being done.
- Stakeholders had difficulty identifying measures of success for the coordination of the research response, which were separate from measures of success for coordination in the broader research system.

Given these conditions, it is important to recognize that any short-term, pandemic-focused research coordination efforts may have a limited impact. This does not mean the efforts are not worthwhile, especially if they lay a foundation for longer-term system change. Rather, it requires having realistic expectations about what can be achieved from primarily informal coordination in the short-term and learning from the experience of stakeholders involved in the COVID-19 research response to suggest what needs to be addressed in the health research system to more effectively support health policy, planning, and care/service delivery over the longer-term.

4. Findings

This section presents the key findings of the rapid review of the coordination aspects of the provincial COVID-19 research response.

4.1 Experiences of coordination: four analogies
Analysis of stakeholder responses suggest there were four archetypical experiences (analogies) of coordination in the context of the COVID-19 research response. These experience analogies are not mutually exclusive at the individual level. They are intended as a framework for contextualizing stakeholders’ responses to the specific coordination initiatives associated with the research response.

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8 Complex systems are characterized by non-linearity (small actions can lead to large reactions), emergence (patterns emerge from self-organization among the elements), dynamic interactions (interactions between parts of the system can be volatile and unpredictable), adaptive (interacting elements respond and adapt to each other) and uncertain (outcomes are unpredictable in advance).
Puzzle piece analogy: The vast majority of stakeholders interviewed for the rapid review were able to confidently report only on the aspects of the research response, and response coordination, for which they were personally responsible: their “piece of the puzzle”. Many respondents indicated they were vaguely aware of some of the more prominent coordination initiatives, but could not comment on their purpose, progress, outcomes, or how they fit together. Even some of those responsible for major, related coordination initiatives indicated they were unclear about the purpose, scope, and progress of other initiatives. Only three individuals interviewed for the project had a “whole picture” perspective of the provincial coordination of the research response.

Friends analogy: Where coordination was successful, it appeared to be largely dependent on existing relationships between well-established individuals, specifically University of British Columbia (UBC), BC Centre for Disease Control (BCCDC) and, to a lesser extent, Vancouver Coastal Health (VCH). For example, some researchers have contracts to provide specific data or analysis to research users; other researchers who are well-known in their fields were directly approached by research users to provide data and analysis (i.e., commissioned research). Several instances were noted of a single individual serving as a lynchpin between the decision-maker with an identified need, and the researcher(s) who could best serve that need. At the more systemic level, when discussing their successful interactions with different coordination initiatives (e.g., SRAC, CRCI, PC-ICCN), many respondents referred to key people by name and attributed the success of the “coordination” to their interactions with those individuals.

Black box analogy: Many stakeholders engaged for the rapid review experienced coordination of the research response as a “black box”. Some health system leaders (at the output end of the “black box”), for example, indicated that they did not know the details of how the coordination was happening (and indeed had no need to), simply that it appeared to be working because they were getting the answers they needed. Other health system leaders had the opposite experience; with their understandable focus on health care delivery during a fast-evolving pandemic, they did not know what coordination was being attempted and they were not aware of what emerging research could be used, or was being used, for decision-making. On the other side of the black box (the “input” side), a common theme among researchers was that the process of getting their research to where it could be used for decision-making was opaque. It is important to note that this “black box” view of coordination around the research response appeared to be reflective of many stakeholders’ experiences of the research ecosystem in BC more broadly.

“Drop in the bucket” analogy: Finally, a large proportion of stakeholders experienced coordination of the COVID-19 provincial research response as positive and well-intentioned, but a drop in the bucket compared to what is needed to address the magnitude of challenges and barriers in the research ecosystem that prevents multi-institutional COVID-19 research from getting to where it is needed, when it is needed. The experience of just trying to get things done – to get research projects through all the pathways and levels of approval (particularly in health authorities), obtain data, or to formalize coordination structures and mechanisms – was a frustrating experience for many researchers and health authority research support staff, as well as for some of the shared infrastructure leaders. For many experienced researchers and support staff, this was distressing but not surprising; the distress appeared

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9 According to the Merriam Webster Dictionary, a black box is “anything that has mysterious or unknown internal functions or mechanisms.”

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to be linked to a sense of lost opportunity for how research could have so much better supported the COVID-19 response. For other stakeholders doing multi-health authority research for the first time, the experience of confusion, roadblocks, and delays “shone a light” on lack of coordination in the broader research ecosystem. For still others, what was previously accepted as normal became unacceptable in the context of a pandemic requiring a rapid research response.

The specific coordination actions, successes and challenges are discussed further in the following sections.

4.2 What actions have been implemented?

As noted above, defining the boundaries of “the response” was challenging, as it evolved throughout 2020 in response to the shifting pandemic and as different stakeholders became engaged in different ways. Broadly, there were three types of interventions: new, formal structures and processes (some envisioned and planned from the earliest days of the pandemic, and others emerging organically); efforts to pivot, streamline and strengthen existing processes and structures; and informal processes to improve communication. A summary of some of the key initiatives is provided below, primarily to provide context for the more fulsome discussion about the successes and challenges of the response that follows in subsequent sessions. More information about what was implemented as part of the research response is provided in Appendix A.

4.2.1 New formal structures and processes

Stakeholder interviews and document review identified a number of new coordination initiatives that were implemented through the COVID-19 provincial research response. These are shown in the figure below, in descending order of stakeholder awareness.

- Rapid, significant infusion of research funding
- Rapid research competitions and projects, aligned with provincial priorities (e.g., MSFHR, Genome BC)
- BC COVID-19 research symposia
- Strategic Research Advisory Committee (SRAC)
- COVID-19 Clinical Research Coordinating Initiative (CRCI)
- Post-COVID Interdisciplinary Clinical Care Network (PC-ICCN) / Post-COVID-19 Recovery Clinics
- Inventory of COVID-19 Research (BC AHSN)
- SRAC Research Frameworks

In addition, in 2020, $15M in provincial funding was announced for a pandemic institute hosted by Simon Fraser University (SFU), and $10M was announced for the BCCDC Foundation to fund research on infectious diseases; however, at the time of writing, it was too early to consider these as part of formal coordination initiatives.
4.2.2 Efforts to pivot, streamline and strengthen existing processes and structures

There were a number of efforts to pivot, streamline and strengthen existing processes and structures to facilitate rapid COVID-19 research. These built on the foundations of existing partnerships, collaborations and processes for multi-institutional studies and use of shared infrastructure. Key efforts included:

- Rapid ethical review process for COVID-19 clinical research through Research Ethics BC
- Health Data Platform
- Rapid data access protocols
- REACH BC

Some respondents were also aware of incremental changes in health authority structures to enable better coordination of COVID-19 research and knowledge translation efforts. A key example of this was enhanced processes for coordination and communication between health authority research departments. This enabled better knowledge mobilization, information-sharing and shared solution-finding for resource challenges and divergent processes to support clinical research across the health authorities.

Stakeholder awareness of all these efforts was limited apart from the attempts to streamline ethics review, and among those who were directly involved in them.

4.2.3 Informal processes to improve communication between groups of researchers, and between researchers and decision-makers

Stakeholders also commented on a number of informal processes that emerged spontaneously, for example:

- Where there were lessons learned that could be shared with others in similar positions.
- In response to events where better communication might have prevented tensions or duplications.
- To prevent duplication of effort in the first place.

This included communications between different units within the Ministry of Health and the research community, and the BC COVID-19 Clinical Trials Network. There are likely many other examples; a fulsome documentation of these was outside the scope of the rapid review.

4.3 Successes and qualified successes

4.3.1 The view from the top

Provincial-level health system leaders interviewed for this review perceived that overall, the coordination of the provincial COVID-19 research response has been successful.

“Success, to me, is being able to turn to our group and say ‘Oh, this new question has arisen: what do we know about it?’ And to know that there’s people who’ve been thinking through it and connecting with each other and can say, ‘Well, we’ll talk to [name] in the lab and she’ll be able to connect with somebody at [institution] who’s been working on this issue and we can get you an answer.’ … For me, I believe it’s been a success story in how we have coordinated.” – Provincial health system leader
4.3.2 An “impressive start” in the right direction
Stakeholders noted that there was significant and “impressive” informal collaboration at the outset of the pandemic, with researchers and decision-makers across the board recognizing the importance of coordination to the success of the provincial research response. Many of the formal structures began or grew from relationships between well-positioned individuals, some with more direct engagement or direction from the PHO than others. Most stakeholders felt that the coordination efforts were well-intentioned, necessary and a step in the right direction for both coordination of the research response and as a foundation for improved coordination of the health research system in the longer-term.

“I was really impressed with how quickly the BC community can come together to talk about big issues as they’re evolving.” – Shared infrastructure leader

4.3.3 Leadership
Many stakeholders commented on the importance of strong leadership for the successes of coordination of the research response. This included both institutional and individual leadership:

- Provincial Health Officer – by directing the requirement for research coordination in the earliest days of the pandemic.
- BCCDC – by modelling effective internal coordination, and through the external coordination leadership of its Director of Research, Dr. David Patrick.
- MSFHR – through its long-standing and respected role as a broker between the research community and decision-makers.
- UBC – through the strength and breadth of its research community and academic leadership.

4.3.4 A single point of contact
One name emerged repeatedly from across interviews with a variety of stakeholders – Dr. David Patrick – as a key player in the coordination effort. Stakeholders at multiple levels throughout the research response valued having a single senior point of contact who has served as a consistent conduit between the research community, BCCDC, the PHO and MoH.

4.3.5 Rapid research funding
The rapid and substantial infusion of research funding to established institutions and researchers was perceived by many stakeholders as the most important contributor to success of the research response. This includes seed funding for rapid response public health questions (e.g., MSFHR, Genome BC), direct infusions of funding to research organizations, and research competitions. Some stakeholders observed that competition funding was almost “too quick” in some cases, catching researchers off guard and narrowing the scope of responses (both geographically and in terms of non-academic research). Regardless, the rapid infusion of funding to support research was broadly seen as an early success.

4.3.6 Leveraging existing infrastructure and partnerships
Stakeholders observed that the coordination efforts were able to successfully leverage existing infrastructure and partnerships. Many examples were provided, the most common of which were BCCDC (and its existing relationships with university-based researchers and Genome BC), existing networks of clinical researchers, health authority research departments, Population Data BC, Research
Ethics BC and the existing harmonized ethics review process, and the BC SUPPORT Unit. Existing partnerships between BC funding agencies and their federal counterparts were also mentioned (e.g., MSFHR-CIHR, Genome BC – Genome Canada).

4.3.7 BC COVID-19 Strategic Research Advisory Committee (SRAC)

SRAC was broadly perceived as a useful structure. Its role as a conduit between researchers and the PHO, through its Co-Chairs, was particularly valued. Beyond the leadership, much of SRAC’s value to date appeared to be derived from its composition of well-connected senior leaders from a broad spectrum of research and knowledge user organizations and perspectives – people who represent a variety of “lenses” and are “in the know” about what research and research support is needed, and who is doing it.

There was considerable awareness of SRAC being influential in identifying research priorities, and some evidence of institutional consultation (e.g., between funders and SRAC). Most stakeholders who had an opinion about SRAC felt that it should continue to play a central role in coordination of the ongoing provincial research response.

“[SRAC] is a phenomenal and well-respected group of people. And I think just listening to them and hearing their perspective and the conversations they’re having, what do they see as important work. Now that there’s a vaccine out there, there’s still a lot we don’t know ... And what are their thoughts of where we should focus? Because I think they’ll have a lot of sway, given their level of knowledge and experience.” – Shared infrastructure leader

However, most stakeholders who were not themselves directly involved with SRAC had only a vague understanding of SRAC’s ongoing role and mandate. There was also low awareness of the COVID-19 Strategic Research Framework (especially the second issue) and little evidence of instrumental use of either version.

4.3.8 Initial clinical research coordination

Many stakeholders felt that clinical research coordination was strong in the early days of the pandemic, when hospitals, individual physicians and researchers were being inundated with requests to participate in collaborative research. Without detailed knowledge of the relevant formal structures, many stakeholders described how a network of clinical researchers from a variety of disciplines came together to discuss and consolidate clinical research requests, determine feasibility, link researchers into teams, set up shared resources and organize data and data access.

“What I witnessed at UBC with those clinical researchers was incredibly impressive, where there’s not necessarily a strong history, I gather, working cross-discipline and cross-body system. That was very good.” – Health system leader

Several stakeholders talked about the early days of coordination to set up a COVID-19 patient cohort for research, and to feed learning back into clinical care, as a particular success.

These early coordination efforts led to the creation of formal structures (CRCI and PC-ICCN); however, many stakeholders felt that the initial momentum to coordinate clinical research was lost over the summer of 2020 when COVID-19 cases went down and had not been fully regained.
4.3.9 Progress on key “bottleneck” areas of research infrastructure
Stakeholders who were integrally involved in key areas of research infrastructure were able to confidently report acceleration of effort and concrete progress in some key “bottleneck” areas of the research system. For the most part, the impacts of progress were not yet widely visible to the research and research support community; however, it would be remiss not to note progress in long-standing areas of challenge, where this happened.

Data sharing and access
According to individuals involved in its development, work on a provincial Health Data Platform (HDP) has been underway for some years but accelerated during COVID-19, in anticipation of more urgent data access needs. This required a higher level of urgency for collaboration between MoH, health authorities, PHSA and Population Data BC than had previously been seen. The capacity, capabilities and governance for data access have now been established, and data sets will continue to be added gradually.

Individuals involved in the HDP’s development acknowledged that the impact to date for researchers has been “negligible”, but the plan is for the HDP to eventually address some elements of multi-institutional operational approval that are currently major barriers for multi-organizational research (e.g., privacy review and approval, contracts around data access and sharing).

“The Health Data Platform is a thing we’ve been talking about for a long time. I don’t know if our assets have been as strong as people hoped, but the fact that we can actually link data, that it’s in the cloud. It’s an impressive array of data.” – Health system leader

Research ethics review and approval
There were mixed views among stakeholders as to whether the research ethics approval process had improved. The rapid ethics review for clinical research, which built on the foundation of the broader harmonized ethics review process, did work very well for some researchers, and there was hope that this structure will serve as a foundation for clinical research ethics approval beyond the pandemic. However, the rapid review process was not available to the full range of researchers, and harmonized review continued to pose challenges as researchers struggled to meet some health authorities’ individual requirements (see Challenges below).

“I don’t know if in fact it has worked as well as I thought. I’ve heard people saying that the ethics part didn’t actually work as smoothly as it was described to me … I still think it was an asset, it had the ability to move in a much faster way than if we did not have it.” – Health system leader

Consent
The launch of the REACH BC platform mid-pandemic, as a provincial mechanism for obtaining consent to contact patients for follow-up, was seen by some as an important achievement. Although it was not designed for the type of quick response permission-to-contact needed for all COVID-19 research, nor is it accessible for all those who may be interested in participating, the fact that it has been launched and is being piloted in “real time” is generating useful lessons that can be carried forward for broader patient engagement in the future. A very small number of researchers expressed concern that the REACH platform is being promoted as the only option for registering patients for follow-up, and that this would result in some critical patient populations being excluded from research.
A very small number of stakeholders also indicated that there had been some conversation regarding standardized patient consent protocols, but from the outside, it was unclear whether this cross-health authority conversation had progressed.

Privacy review and approval
A very small number of stakeholders also indicated that conversations about harmonized privacy review were starting to accelerate, facilitated by the BC AHSN. From the outside, it was unclear how far the conversations had progressed.

4.4 Challenges
The majority of challenges for the coordination aspects of the COVID-19 research response appear to relate to long-standing problems of coordination in the broader research system. Many respondents indicated that the impact of COVID-19-specific coordination has likely been limited because of these problems. Within this context, the rapid review revealed two types of challenges: those which are conceivably within scope for a provincial COVID-19 research response (but reflect challenges in the broader ecosystem), and those that are clearly beyond the scope of a COVID-19 research response.

4.4.1 Response-specific challenges and opportunities for improvement
Confusion about the purpose, scope, and authority of the coordinating bodies for the research response
A common theme from the interviews was confusion about “who is in charge” and accountable for various aspects of coordination required for an efficient COVID-19 provincial research response.

“The fundamental problems that people have been complaining about, worried about over the past few months is there’s no clear path to a final decision. We have all of these conversations, all of this willingness to do things differently, but it’s not clear who gets to have the final say and how it gets to implementation and then kind of command that this decision be followed. It’s like everybody’s in charge, and no-one.” – Shared infrastructure leader

Patient consent was one of several issues that illustrate this challenge:

“A concrete example is everyone wanting to get patient consent. If we wanted to do something like universal consent, where you sign something, say like this is an emergency, you can do whatever you want with my samples for anything related to COVID, who actually has the authority to do that? Even if you figure out who the authority might be, it might be someone high up, how do you actually get there, who are the right people to make this happen efficiently?” – Academic leader

Many stakeholders who were aware of SRAC, CCRI and/or PC-ICCN expressed some confusion about the purpose, scope, and authority of these bodies. The PHO’s and MoH’s role in governance of the provincial research response was also not clear.

“The committees, nobody knew what committees were happening, committees were being created. As a researcher, how do you even understand when a committee was created, who you would submit to? How did they even have the authority to approve or not approve your research?” – Researcher
Many stakeholders understood that a key purpose of SRAC was to identify priorities for provincial COVID-19 research. However, it was unclear whether SRAC has meaningful power to command adherence to the priorities, when there is no funding to use as leverage, and what role SRAC plays in coordination of the research response and knowledge translation. It was also unclear where, or to whom, SRAC ultimately reports; this was thought to have become more confusing since the early days of pandemic research coordination.

“I don’t know who the Strategic Research Advisory Committee reports up to in the response. I think it was really clear in March, April, May. It has not been clear since.” – Health system leader

Several stakeholders expressed confusion between the functions of CRCI, SRAC and PC-ICCN, particularly for the coordination of the research response. Firstly, there appeared to be some confusion about whether CRCI stands for Clinical Research Coordination Initiative, or COVID-19 Research Coordination Initiative. This raised the question about whether its remit is purely clinical, or broader; if the latter, how its role is distinct from SRAC’s. If the former, it is not clear how its role is distinct from PC-ICCN.

At least one researcher raised questions about the Office of the PHO becoming involved in governance of the research function in ways that they had not previously. A specific example provided involved a directive from the PHO that researchers were not permitted to phone patients directly for follow-up, even though ethics approval from the relevant health authority had already been granted.

The lack of clarity around mandates, and where exactly “the buck stops” led to frustrating delays in decision-making:

“It took almost a year for government endorsement of a network that we’ve been talking about for at least six months, in the middle of this, you know, absolutely once-in-a-lifetime crisis. That’s a very concrete frustration.” - Researcher

Maintaining momentum on coordination

There were mixed views about whether the coordination of the research response has improved or deteriorated since the initial “flurry” of coordination activities in early 2020. Some stakeholders felt that coordination structures had matured, and areas of overlap were moving towards resolution, while others (largely outside the leadership of these structures) perceived that there had been less coordination as the pandemic unfolded. However, many stakeholders expressed concern that as the vaccines roll out and the acute phase of the pandemic recedes, there would be less urgency to press on with the coordination changes necessary for an effective health research system that is prepared “next time”. Stakeholders expressed a strong desire to maintain legacy effects from the COVID-19 research response coordination.

Inclusiveness and equity

Nearly all stakeholders acknowledged that the initial research response was led by well-established individuals at UBC and BCCDC. For some stakeholders, this was considered understandable, as speed of response was considered to be of the essence, and UBC’s and BCCDC’s strong leadership was acknowledged. However, the absence of a patient perspective in the initial coordinating structures, SRAC particularly, was perceived as a big omission.

“When SRAC was first created it was very obvious to the patient partner community that patient partners were not included or considered as part of that consultation. We have really missed the
...mark on engaging with patients and members of the community who are deeply impacted by a lot of the work that we’re doing ... They have tried to, you know, patch it up, so I think they’re getting there but really, I still think it’s a big gap.“ – Patient partner

Although this was perceived to have improved with the addition of new SRAC members, with support from the BC SUPPORT Unit’s network of patient partners, some stakeholders expressed concern that the patient / public perspective was not truly integrated across all aspects of the research response.

Stakeholders also had concerns about the coordination of the research response still being focused on what the main Lower Mainland academic centres have and need.

“Research is very much focused on the large academic regions of the province. And so, the north, or the interior, tends to be overlooked when scaling up research projects.” - Researcher

Other stakeholders framed these gaps in terms of equity and expressed particular concerns that the response “agenda” was not paying sufficient attention to those population groups that may be most disadvantaged (in terms of health and also broader outcomes) by COVID-19 and who had least access to influence priorities or participate in research. For example, there were some concerns that insufficient attention was being paid to racialized communities, people on low incomes, people who are homeless and people who have mental health or substance use challenges. It should be noted that equity issues are addressed in both issues of the SRAC framework; however, explicit attention to equity may need to be incorporated into mandates for provincial coordinating bodies such as SRAC, CRCI and PC-ICCN.

Need for greater emphasis on knowledge translation
Several stakeholders commented on the need for greater emphasis on knowledge translation in the provincial response. Some observed that while there were smaller or project-specific initiatives that have been helpful, knowledge translation did not appear to have been sufficiently embedded in some of the funding calls or as a key function for SRAC. Even events such as the COVID-19 research collaboration symposia were thought to have placed more emphasis on sharing between researchers, than between researchers and decision-makers.

“For me, the coordination of the research is one thing, but this is a massive knowledge translation challenge. We still need to maximize as much as possible the translation and sharing of evidence with appropriate policy people.” – Health system leader

More emphasis on public health, social determinants of health and the social and economic consequences of COVID-19
Several stakeholders felt that there needs to be greater attention paid to research in public health, the social determinants of health, and the social and economic consequences of COVID-19. It was unclear to stakeholders whether current “unintended consequences” work (for example, within the Ministry of Health) could stretch to include social and economic consequences of the COVID-19 pandemic in their own right, and not just as social determinants of health; the same question applied to SRAC’s mandate, given that its membership is currently very much health-focused. Stakeholders questioned which BC bodies are responsible for funding and coordinating this kind of research, given there is no provincial equivalent of the Social Sciences and Humanities Research Council (SSHRC), and whether this was a gap that SRAC should pay attention to.
“Where do projects sit that don’t involve COVID patients, but explore the impacts of COVID? It’s not clear to researchers what kind of supports are available, where to go for collaboration. It makes people wonder if there’s support, is it worth the effort to put in a great proposal, are they even going to consider the project?” – Researcher

Some stakeholders also indicated that coordination in these areas may need greater attention. For example, one stakeholder pointed to the existence of 125 separate surveys on COVID-19-related topics. Other stakeholders pointed to the absence of a rapid harmonized ethics process for non-clinical projects. Still others noted a more general absence of focus on coordinating public health research, resulting in duplication of studies and study requests and absence of streamlining processes that prevent health authorities and health authority researchers from participating.

Communication about the Province’s coordination efforts
Finally, stakeholders observed that since the initial coordination efforts in the spring of 2020, there has been inconsistent communication about the Province’s coordination efforts, particularly from SRAC.

4.4.2 Broader health research system challenges
The most significant coordination gap for the COVID-19 research response appears to be support for research across multiple health authorities. In particular, the health authority operational review process and lack of institutional structures to support research were seen as critical barriers to an effective COVID-19 provincial research response.

Illustrative examples
Five examples, drawn from data collected during this review, are provided to illustrate broader health research system challenges involving the health authorities:

Example A - Challenges with health authority institutional approvals, particularly privacy
Researcher A received funding from several BC sources for a national COVID-19 clinical research study involving over 50 sites in multiple provinces. After obtaining ethics approval through the rapid harmonized review process (“that worked really well, five stars out of four”), the researcher set about obtaining institutional approval from five regional health authorities (“that was a disaster”). The researcher was able to obtain institutional approval fairly easily in some health authorities. In others, institutional approval was held up in negotiations with individual privacy and contract officers, who interpreted provincial privacy laws in varying ways and in ways that felt like “endless roadblocks, and obsession with minutiae”. With the help of research support staff at two different health authorities, the researcher finally obtained institutional approval. However, by this time, data collection was four months behind (on a one-year grant), and the research team were not able to catch up. The research design called for patient follow-ups, at three different intervals; the team missed the first two for the BC sites, resulting in total data loss for that part of the study.

Example B – Lack of support for researchers outside the Vancouver hub, doing multi-health authority research.
Researcher B received a COVID-19-specific grant from a BC funder to study health outcomes of front-line workers across multiple health authorities. The researcher was fairly new to BC and to
Canada and had not previously needed to navigate BC’s health research system. Despite using the harmonized review process, obtaining approval had so far taken six months. The researcher was uncertain whether they made mistakes in their application or sent the application to the wrong place for approval, or whether there was some other reason for the delay. Being new to BC, and situated outside the Vancouver academic “hub”, the researcher did not have significant resources to draw on to resolve their ethics approval difficulties. Data collection had yet to begin.

Example C – Challenges with multi-health authority data quality and access
Researcher C was using administrative data from six different health authorities for COVID-19-related research. They reported having to submit six different data requests, in six different formats. The data were different in each health authority because the variables were different, and the data were collected differently. Some of the individuals they were working with at the health authority to obtain the data changed, and they had to go back to “square one” to explain the research and the specific data needs. The researcher was avoiding certain analyses that they knew would be useful for addressing some priority COVID-19 research questions, because they knew that it is just too challenging to access and analyze the multi-institutional data.

Example D – Challenges obtaining multi-health authority ethics approval for non-clinical research
Researcher D was using a mixed-methods approach to build and refine some COVID-19 models. The qualitative dimension of the research involved interviewing decision-makers in each of the health authorities. Because it was not clinical research, there was no rapid harmonized review process. Each health authority had to review the ethics application and sign off. Even though the research design called for a single interview (i.e., one person, typically a medical health officer) in some health authorities, some health authorities required that the researcher identify a partner in the health authority, which would have been inappropriate. The process to obtain ethics approval took five months of “back and forth” questions, emails, and phone calls with multiple health authorities. In the end, the researcher had to release the main findings (the models) without input from decision-makers in order to provide information that was sufficiently timely to support decision-making.

Example E – Consequences of “adding up” individual researchers’ challenges with the health research system
MSFHR funded 20 COVID-19 research projects in two spring 2020 intakes. The projects were expected to produce results within one year. The midterm reports found that 7/20 were delayed; closer examination of the reports and interviews revealed that two others experienced challenging delays but had changed course in order to keep the projects on track. Of the nine delayed projects, seven (one third of all MSFHR-funded projects) highlighted challenges with health research system-related issues, including:

- Obtaining permission to contact patients.
- Delays or difficulty obtaining ethics approval.
- Data access or delays in data transfer.
- Difficulties in obtaining complete and accurate datasets.
Other researchers who reported their projects as being on track also mentioned health research system barriers, including organizational standard operating procedures for data access, specimens for research (i.e., biobank), delays in obtaining ethics approval, and general difficulties obtaining institutional research approval.

Provincial oversight for the health research system

The confusion about the purpose, scope, and authority of three of the key coordinating structures for the provincial COVID-19 research response was thought by many stakeholders to reflect the broader landscape of provincial decision-making and authority for health research:

“And what I didn’t understand, what I still don’t understand, is just a fundamental flaw in BC overall, in terms of, you know, whenever there’s a big health issue, what group, and what organization has authority?” - Researcher

Many stakeholders highlighted the need to strengthen provincial oversight of the health research system, which would include setting expectations for health authorities’ participation in research and in solving coordination issues and reducing or eliminating health authorities’ individual adjudication processes for approval.

“I think we have to have some provincial tables that just eliminate the health authority by health authority review and adjudication. I think there needs to be an expectation that there’s one ethics review, one privacy review. I do think it comes from setting expectations from a higher level, and then supporting people to have those coordinated conversations.” – Shared infrastructure leader

Health authorities would also need to be more comprehensively engaged in determining research priorities, and support to engage in coordination activities, in order to facilitate buy-in for the use of scarce resources.

Several stakeholders indicated that stronger leadership, direction, and support from the Ministry of Health would be required to make this collaboration with health authorities happen.

“Where the work needs to happen is the research culture within the health authorities, and you don’t get that without some sort of legitimization or focus from the Ministry. We can wave our flags as hard and as fast as we can, and we can do good work in small pockets. But until we have something from a coordinated body that’s got some decision-making power and direction, it’s not going to happen.” – Health authority research department staff

Addressing focus areas: ethics review, privacy review, data governance

Stakeholders consistently mentioned ethics and privacy review and approvals as two areas to focus on for a standardized approach. Some stakeholders thought the process used to build the current harmonized ethics review could be replicated to create a fully standardized ethics review system (i.e., one application, one set of requirements that all the health authorities agree to), and a standardized privacy review system. The existence of a legislative framework for privacy was also thought to be a “reason” to pursue a standardized approach, as it should not be left to individuals in each health authority to interpret privacy laws in different ways.
“We should have a central coordinated mechanism similar to Research Ethics BC, that reviews the privacy considerations and interprets that privacy legislation in the same way.” – Health authority research department staff

Data governance was another area that stakeholders commonly felt should be a focus for standardization at the provincial level. Governance covers a myriad of standards, policies and processes that are beyond the scope of this review to describe in detail, but the processes put in place through clinical research coordination (as part of the provincial research response) and the Health Data Platform serve as starting points.

Health authority research capacity
The explosion of COVID-19-related research requiring engagement by health authority staff highlighted significant gaps in health research authorities’ capacity to participate in research. In the first instance, it was unclear to stakeholders in the health authorities whether there was sufficient consideration for feasibility before research involving the health authorities was approved for funding:

“The problem is the logistics of implementing a research project when we are full out responding to the crisis and immunizing, because it’s not going to work. Our staff don’t have time to gather data that might help your research ... I understand the frustration of researchers dealing with multiple health authorities. From our point of view, we don’t have infrastructure that can even support responding to some of these requests.” – Health authority leader

Health authority staff may not have the skills or training to participate in research; or they may have the skills, but research is not in their job description. For example:

“We did not know that the doctors had agreed [to participate in the research]. They were put down in the ethics application to do the research, but they had never done research before. They were not trained. They had no idea that there were other resources they would need.” – Health authority research department staff

“If you want research to be part of what they do, if you want to talk about preparedness, a part of it is that their job descriptions have to be prepared. They have to have the opportunity within their job to have the training and to keep it updated.” – Health system leader

Finally, the role of health research departments was considered vital to building research capacity in the health authorities; nearly all the researchers interviewed for the rapid review indicated they had received excellent support from these departments to navigate the complexities of gaining ethics and/or operational approvals. However, personnel in these departments observed that it is a constant battle to have research and research infrastructure recognized at senior leadership tables as being an important element of providing excellent patient care.

Once again, the role of Ministry of Health leadership in making this happen was recognized:

“Everything I’m saying will not happen unless it comes directly from the Ministry of Health and it’s put into the mandate letter. And the mandate letter says, ‘You will have adequate infrastructure to be responsive to research needs in priority areas, as well as effective mechanisms for translating research evidence into practice at your health authorities.’” – Health authority research department staff
Increasing alignment of funding to provincial priorities

Within the limits of the funding it has been able to direct, SRAC was considered to have done a reasonable job of identifying provincial COVID-19 research priorities. However, given that a large proportion of funding for research is not directed by the Province, and even less so by SRAC, some stakeholders expressed concern that there will continue to be misalignment of BC priorities and actual research performed.

“So, an organization like Michael Smith Foundation, I guess can align through funding from the Ministry of Health, which MSFHR then translates into a call, but there’s going to be limited dollars associated with that. You’re still going to get the larger dollars in places like CIHR and others. So how do you align the priorities for BC when the big money comes from somewhere else?” – Academic leader

A handful of stakeholders wondered whether it may be time to move away from funding competitions to which researchers apply, to a more directive approach.

“Our current model of research funding is that when someone gets a project idea, if it’s on a priority list they apply for it and they say, ‘we’ll do it’, without really appreciating the system that needs to be directly involved in it. And so instead of making like an individual researcher answer that SRAC prioritized question, the province should be answering that SRAC question. And that’s less like shovelling funding towards researchers, and more embedding the research within all aspects of care.” - Researcher

A small number of stakeholders also believed there needed to be greater transparency about where, how, and how much the Province directly invests in research that is not tied to research competitions, so that the value and impact (or not) of such research expenditure can be publicly tracked and used to support more effective provincial investment decision-making.

4.5 Measuring success of the COVID-19 research response in the longer-term

The rapid review explored the development of an evaluation framework for the coordination aspects of the COVID-19 provincial research response. Two key questions the rapid review aimed to address were (1) what would be the purpose of such an evaluation, and (2) how might “success” be measured in the longer-term.

The review revealed that the challenges of separating the COVID-19 provincial research response from the broader research also apply to evaluation, which meant that it was difficult to identify the boundaries for what should be evaluated (i.e., “the response”) and to define a meaningful purpose for an evaluation focused on the coordination of the pandemic-specific research response.

When asked how they would define success for the COVID-19 research response, it was extremely difficult for most respondents to isolate any specific, measurable short- or medium-term outcomes that could serve as indicators of a successfully coordinated COVID-19 research response: the inputs, outputs and outcomes of the COVID-19 coordination response were seen to be simply too intertwined with the broader research ecosystem, and agency for effecting change within the broader research ecosystem does not lie within scope for the provincial COVID-19 research response.

The original vision for an evaluation framework focused on the coordination aspects of the COVID-19 provincial research response may need re-thinking.
5. Concluding remarks

While some important steps were made towards coordination of the provincial COVID-19 research response, which included significant, voluntary and collegial efforts on the part of many individuals and organizations, the rapid review findings revealed that there was not an integrated and sustained provincial research response to the pandemic, a public health emergency. There is an opportunity for the Province to critically reflect on the learnings from this review, and those provided by other provincial initiatives and organizations, to take steps to design a fit-for-purpose, integrated health research system, capable of addressing BC’s current and future health challenges.
Appendix A. Structures and Processes Implemented as Part of the COVID-19 Provincial Research Response

New, formal structures and processes
A number of new formal structures and processes were implemented to support the COVID-19 provincial response. These included, but were not limited to:

- **Rapid, significant infusion of research funding**: At least $250m was released for COVID-19 related research in BC in the first and second quarters of 2020. Federal funding sources included the Ministry of Innovation, Science and Economic Development (ISED) Innovation Supercluster Initiative, Canadian Institutes of Health Research (CIHR), National Sciences & Engineering Research Council (NSERC) and Genome Canada. Provincial sources included MSFHR, Genome BC, UBC Strategic Investment Fund, as well as direct investments from the Province to BCCDC, universities, and health authorities.

- **Rapid research competitions and projects, aligned with provincial priorities**: MSFHR launched a research competition aligned with provincially identified strategic priorities, as well as four projects requested by the PHO to address research urgent priorities. MSFHR also partnered with CIHR to co-sponsor projects to direct funding into the province that addressed BC COVID-19 research priorities. Genome BC also funded 13 short-term projects through a COVID-19 Rapid Response Program, supported Genome Canada’s CanCOGeN Program to sequence 150k viral and 10k patient genomes, and supported several COVID-19-related Digital Supercluster projects.

- **BC COVID-19 Research Symposia** (April, September 2020): The first symposium was hosted by BCCDC and UBC, and its focus was sharing of information about COVID-19 research between researchers, to facilitate collaboration and share resources. The second symposium, co-chaired by SFU and UBC, with support from MSFHR and the BC AHSN, brought together BC researchers working on COVID-19 research with a focus on population and public health, and health services. Its aim was to promote provincial coordination by increasing awareness of COVID-19 research, identifying and catalyzing synergies across early-stage research, and facilitating knowledge exchange.

- **Strategic Research Advisory Committee (SRAC)**: SRAC was set up as a bridge between the BC government and BC’s health research community. SRAC is co-chaired by MSFHR and BCCDC, and its members include representation from MoH, health authorities (including the First Nations Health Authority (FNHA) and Provincial Health Services Authority [PHSA]), academic institutions and patient representatives. SRAC provides advice to the Province on the priorities, funding, coordination and dissemination of research projects and their results to support the health system response.

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10 Genome BC’s first rapid response funding competition was launched prior to the formalization of provincial research priorities. In the case of both MSFHR and Genome BC, the second call for proposals was generally seen as more aligned with the provincial priorities than the first.

• **COVID-19 Clinical Research Coordinating Initiative (CRCI)**\(^{12}\): The CRCI is a province-wide program aimed at creating innovative health systems and structures capable of capturing and collating collective input and feedback to enable the prioritization and coordination of COVID-19 translational research. Six working groups support the work of the CRCI: clinical research, fundamental biomedical research, biobanking, data science, industry liaison, and psychosocial\(^{13}\). The CRCI was initiated and is hosted by UBC, and is a provincial initiative.

• **Post-COVID Interdisciplinary Clinical Care Network (PC-ICCN) / Post-COVID-19 Recovery Clinics** (PHSA)\(^{14}\): The PC-ICCN began as a funded research project involving development of a Metro Vancouver COVID-19 patient cohort to track respiratory outcomes and provide clinical guidance. The project was expanded to include a variety of outcomes (e.g., neurological, psychiatric, kidney, heart) as well as to other health authorities. The Network has now been formalized under the auspices of PHSA and aims to support the best possible outcomes for people who have experienced serious cases of COVID-19, through practices, education, and research. As of February 2021, there are three post COVID-19 recovery clinics in British Columbia.

• **Inventory of COVID-19 Research** (BC AHSN)\(^{15}\): The BC Inventory of COVID-19 research was designed to serve as the single comprehensive inventory of current COVID-19-related studies and trials (including clinical trials) in BC. As of the end of February 2021, the inventory contained 509 entries. It is important to note that the inventory only contains studies that have gone through research ethics review (e.g., it does not include all Ministry of Health research projects).

• **SRAC Research Frameworks**\(^{16}\): SRAC produced the first COVID-19 Strategic Research Framework in April 2020. Its purpose was to provide a framework for decision-making about COVID-19 research in BC, to align research to the Province’s public health priorities. The framework was refreshed (through a second issue) in December 2020.

Efforts to pivot, streamline and strengthen existing processes and structures

There were a number of efforts to pivot, streamline and strengthen existing processes and structures to facilitate rapid COVID-19 research. These built on the foundations of existing partnerships, collaborations and processes for multi-institutional studies and use of shared infrastructure. These included:

• **Rapid Ethical Review Process for COVID-19 Clinical Research** (Research Ethics BC)\(^{17}\): A rapid ethical review process for COVID-19 clinical studies (including Health Canada regulated clinical trials) was introduced in April 2020. The agreement built upon the existing reciprocity arrangement between

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\(^{12}\) Merriam-Webster Dictionary defines translational research as “medical research that is concerned with facilitating the practical application of scientific discoveries to the development and implementation of new ways to prevent, diagnose, and treat disease”.

\(^{13}\) https://crci.med.ubc.ca/


\(^{15}\) https://bcahsn.ca/covid-19-response/inventory/

\(^{16}\) https://www.msfhr.org/our-work/covid-19-research-response/strategic-provincial-advisory-committee

\(^{17}\) https://researchethicsbc.ca/rapid-review-process/

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health authorities in BC regarding research ethics, and applied their emergency standard operating procedures, such that only one Research Ethics Board (REB) approval was required for approval of a provincial clinical study pertaining to COVID-19. This was an extension of the existing harmonized ethics review process, managed by Research Ethics BC.

- **Health Data Platform** (BC Ministry of Health)\(^{18}\): The Health Data Platform (HDP) supports research and analysis both within the health sector and in academia, by allowing access to health data from multiple sources to be brought together as required, linked, de-identified and analyzed on a single secure platform. The Health Data Platform was launched during COVID-19, with initial access limited to COVID-19 projects that meet prioritization criteria (see below, rapid data access protocols).

- **Rapid data access protocols** (Population Data BC)\(^{19}\): Population Data BC, in conjunction with MoH, MSFHR, BC AHSN and other partners, introduced a number of processes to expedite data access for COVID-19 research. These included:
  
  - Expediting projects funded through MSFHR’s rapid COVID-19 research response program.
  
  - Piloting academic access to the Province’s Data Innovation (DI) Program for priority projects that support BC’s COVID-19 research response and require data from other provincial ministries. This access was piloted ahead of schedule to support the COVID-19 research response.
  
  - Expediting the data access process for COVID-19 research using the newly launched Health Data Platform. COVID-19 research requests funded by Genome BC/Canada, MSFHR and CIHR were expedited, and projects funded by all other bodies were reviewed by SRAC for expedition.

- **REACH BC** (BC SUPPORT Unit)\(^{20}\): The REACH platform was conceived as a demonstration project of the BC Support Unit, to connect researchers with potential research participants and patient partners. REACH BC’s initial launch was delayed due to COVID-19; work on the platform was pivoted to focus on COVID-19 and was launched later in 2020.

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\(^{19}\) https://www.popdata.bc.ca/COVID-19_research_support

\(^{20}\) https://www.reachbc.ca/
Appendix B. Rapid Review Approach & Methods

Rapid reviews are a form of evidence synthesis intended to provide more timely information for decision-making than other standard approaches to research and evaluation. Design options for conducting a rapid review are always limited by timelines. As is frequently the case, the design for this rapid review was also limited by budget. A qualitative design was selected as the most appropriate to address the review questions within the timelines and budget available. The main element of the qualitative design was a series of stakeholder interviews, supplemented by document and website review.

In consultation with MSFHR staff, a set of high-level questions was drafted to guide the review. These questions were reviewed by the SRAC Co-Chairs and senior representatives from MoH and MSFHR and discussed with the full SRAC membership. An initial set of background documents and websites was provided to the consultant by MSFHR (Appendix E). These were reviewed for content that could address the guiding questions and to provide context for the interviews. An initial list of interviewees was generated by MSFHR staff in consultation with the SRAC Co-Chairs and senior representatives from MoH and MSFHR. In some cases, alternates were identified and interviewed if the preferred interviewee was not available. Two interviewees were added to the list in response to gaps in perspective that were mentioned by more than one stakeholder. Thirty-one (31) interviews were ultimately conducted. The final interview list included senior stakeholders from the Office of the Provincial Health Officer (PHO), MoH, health authorities21, universities, patient safety, and funding organizations. The interviews also included patient partners, shared infrastructure leaders, health authority research office staff, and researchers (both academic and clinician-researchers; Appendix C).

A tailored interview guide was developed for each interviewee, depending on their perspective and the topics (within the overall guiding questions for the review) they were expected to be knowledgeable about. The interview questions were open-ended, and the conversation was allowed to flow in an order that made sense to the interviewee so long as all the topic areas were ultimately covered. Follow-up questions were informed by the interviewer’s understanding of the context drawn from the document and website review, insights gleaned from earlier interviews and from ten years’ sustained engagement in health/health systems evaluation in BC. The interviews ranged in length from 30 minutes to one hour; they were recorded and transcribed if oral permission was given (24/31 interviews).

Interview transcripts (and notes, if the transcripts were not available) were organized by stakeholder group and then reviewed as preparation for coding and analysis. An initial set of codes was created in NVivo, based around the guiding questions, and all data entered into NVivo. Inductive analysis was then used iteratively to generate and refine themes. Key documents and websites were revisited several times during analysis to inform each subsequent level of analysis, confirm details and provide triangulation where possible. Initial findings and insights were presented and discussed with MSFHR staff, SRAC Co-Chairs and senior representatives from MoH and MSFHR for collective sense-making, including discussion of the analogies and examples of systemic barriers to multi-health authority research. This stage of analysis also included application of a complexity lens to help interpret the “success” of the coordination and final sense-making of the findings.

21 For the purposes of reporting, senior stakeholders from the PHO, MoH and health authorities are grouped together as “health system leaders”.

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Appendix C. List of Organizations and Stakeholders Consulted

Representatives of the following organizations were consulted as part of this rapid review:

- BC Academic Health Science Network
- BC Centre for Disease Control Foundation
- BC Ministry of Health
- BC Patient Safety & Quality Council
- Fraser Health
- Genome BC
- Interior Health
- Island Health
- Northern Health
- Office of the Provincial Health Officer
- Population Data BC
- Provincial Health Services Authority
- Simon Fraser University
- University of British Columbia
- University of Northern British Columbia
- University of Victoria
- Vancouver Coastal Health

Two (2) patient representatives were consulted.

Additionally, ten (10) academic researchers and clinician-researchers based in a variety of institutions across the province were consulted.
Appendix D. Stakeholder Interview Questions

The rapid review and synthesis were informed by semi-structured interviews with a diversity of stakeholders involved in the provincial COVID-19 research response, guided by the following high-level questions:

1. *What actions* have been undertaken to support a coordinated research response?

2. *What does success look like* for a coordinated research response? How will we know when we get there?

3. In what ways has a coordinated research response approach *created or supported the conditions* for research to influence health care policy and practice? What are some key examples of where policy and/or practice have been influenced because of coordination (e.g. health research + collaboration + shared infrastructure)? What factors made these successful?

4. In what overall areas of research, or research groups, is *coordination strongest or weakest* and why? What are the key enablers and barriers to coordination in these areas?

5. Where does *duplication* in the system to support COVID-19 research exist, and how might this be reduced through increased coordination?

6. What is *missing* from the system that is needed to support better coordination, and how might it be addressed?

7. What is the *role (actual and potential) of the strategic research framework* in supporting more effective coordination?

8. Are there any *unanticipated outcomes* (positive, negative, neutral) from the coordination work to date?
Appendix E. Key Documents & Websites

Websites

- BC COVID-19 Strategic Research Advisory Committee (SRAC)
- Michael Smith Foundation for Health Research (MSFHR) COVID-19 Research Response
- BC Academic Health Science Network (BC AHSN) COVID-19 Response:
  - BC Inventory of COVID-19 Research
  - BC COVID-19 Survey Inventory
  - BC SUPPORT Unit (includes REACH BC)
  - Clinical Trials BC COVID-19 Resources
  - Resources for Research Ethics During COVID-19 (Research Ethics BC)
  - Rapid Ethical Review Process for COVID-19 Research (Research Ethics BC)
- BC Centre for Disease Control (BCCDC)
- COVID-19 Clinical Research Coordinating Initiative (CRCI)
- Post COVID-19 Recovery Clinics (Post COVID-19-Interdisciplinary Clinical Care Network, PC-ICCN)
- Population Data BC Support for COVID-19 Research
- BC Health Data Platform
- Genome BC

Key Documents and Other Information

- BCCDC COVID-19 Research Symposium Showcase
- BC COVID-19 Symposium recordings and transcripts (November 2020)
- BC Health Sector Planning Document (October 2020)
- MSFHR COVID-19 Research Response Fund Grants – Mid-Term Reports (January 2021)
- SRAC Terms of Reference (April 2020, revised November 2020)
- SRAC Research Framework 1 (April 2020)
- SRAC Research Framework 2 (December 2020)
- SRAC Research Framework 2 – stakeholder feedback forms
- SRAC briefing notes and updates to the Office of the Provincial Health Officer