Indirect Impacts of COVID-19: A Case Study of Evidence, Advice and Representation From Consumer and Community Members in New South Wales Australia

Tara Dimopoulos-Bick, BSW, MSW[1] ⓘ **, Louisa Walsh, BPhysio(Hons)[2,3],**
and Kim Sutherland, MSc, MBA, PhD[1]

Abstract

The COVID-19 pandemic continues to affect health care systems globally, and there is widespread concern about the indirect impacts of COVID-19. Indirect impacts are caused by missed or delayed health care—not as a direct consequence of COVID-19 infections. This study gathered experiences of, and perspectives on, the indirect impacts of COVID-19 for health consumers, patients, their families and carers, and the broader community in New South Wales, Australia. A series of semi-structured virtual group discussions were conducted with 33 health consumers and community members between August 24 and August 31, 2020. Data were analyzed using an inductive thematic analysis approach. The analysis identified 3 main themes: poor health outcomes for individuals; problems with how health care is designed and delivered; and increasing health inequality. This case study provides insight into the indirect impacts of COVID-19. Health systems can draw on the insights learned as a source of experiential evidence to help identify, monitor and respond to the indirect impacts of COVID-19.

Keywords

consumer engagement, COVID-19, patient engagement, patient expectations, patient perspectives/narratives, qualitative methods

Background

There are widespread concerns about the indirect impacts of COVID-19. Indirect impacts are caused by missed or delayed health care—not as a direct consequence of COVID-19 infections. Disruptions caused by COVID-19 lockdown measures and staff redeployments have caused delays in cancer (1,2), stroke (3), and heart disease (4) diagnosis and management. The mental health impacts of COVID-19 are well documented, with 1 longitudinal study reporting that mental health in the United Kingdom had deteriorated since April 2020 (5). In Australia, a self-reported questionnaire found that 78% of respondents (3954 people) said their mental health had worsened since the pandemic (6). For older patients, there are concerns that deconditioning, sedentarism, and enforced inactivity through public health measures may impact diabetes management and increase the risk of fractures (7).

While New South Wales (NSW) Australia has recorded relatively low COVID-19 prevalence, there has been significant changes in health utilization across the state. In March to June 2020, compared with the same period in 2019, primary care face-to-face consultations decreased by 22.1%; breast screen activity by 51.5%; ambulance incidents by 7.2%; emergency department visits by 13.9%; public hospital inpatient episodes by 14.3%; and public hospital planned surgical activity by 32.6% (blinded for review). Such decreases are not unique to NSW (8).

The Critical Intelligence Unit (CIU) was established as part of the COVID-19 response for NSW Health (9).

[1] NSW Agency for Clinical Innovation, NSW, Australia
[2] Centre for Health Communication and Participation, Cochrane Consumers and Communication Group, La Trobe University, Victoria, Australia
[3] School of Psychology and Public Health, La Trobe University, Victoria, Australia

Corresponding Author:
Tara Dimopoulos-Bick, NSW Agency for Clinical Innovation, 1 Reserve Road, St Leonards, New South Wales 2113, Australia.
Email: tara.dimopoulosbick@health.nsw.gov.au

In August and September 2020, the CIU conducted a consultation with health consumers and community members to gather experiences of, and perspectives on, the indirect impacts of COVID-19. This case study presents the method and summarizes the key indirect impacts of COVID-19 identified by health consumers and community members involved in the consultation as a source of experiential evidence.

Methods

Semi-structured virtual group discussions were conducted with health consumers and community members in NSW to gather their experiences of, and perspectives on, the indirect impacts of COVID-19. Indirect impacts are caused by missed or delayed health care—not as a direct consequence of COVID-19 infections.

Consumer Involvement in Study Design

One of the authors (LW) is a person with lived experience of lifelong chronic illness who has held consumer representative roles. She was brought into the consultation as a consumer co-facilitator and was involved in the development and facilitation of the group discussions, and the analysis and presentation of the results.

Participants and recruitment. The invitation to participate in the virtual discussions was disseminated through a range of existing organizational networks and through Twitter to reach broader audiences. The invitation was shared through a snowballing approach to reach and broader and more diverse audiences. Participants interested in the virtual discussions contacted one of the authors (TDB) via email or telephone for more information and to confirm their participation in the group discussions.

Data collection. Two of the authors (TDB and KD) created the question guide and facilitated the virtual discussions. The discussions occurred over 3 sessions, each held a week apart: (a) 30-minute online briefing session; (b) 60-minute facilitated discussion, and (c) 60-minute key recommendations session. The virtual discussions were video recorded via Skype, the text-based chat was also captured, and additional notes were taken by the facilitators where required.

Participants received a pack of background information about known indirect impacts of COVID-19 in NSW and other jurisdictions. This information was presented in the first session by 2 of the authors (blinded for review) where participants had an opportunity to ask questions and clarify their understanding of the information presented and the virtual discussion process.

In the second session, participants shared their experiences of, and perspectives on, the indirect impacts of COVID-19. The framing question for session 2 was "when

we think about the indirect impacts of COVID-19 on health systems, consumers and communities, what concerns us?" After the second session, participants were sent the preliminary analysis of their discussion, to enable further comment, reflection, and member checking.

In the third session, participants considered if there were any gaps in the preliminary analysis and ranked the highest priority indirect impacts for NSW Health. The framing questions for the third session were

- "What do we think are the most important indirect impacts of COVID-19 for NSW Health to consider and why?"
- "What key recommendations will we provide to NSW Health about assessing and responding to the indirect impacts of COVID-19?"

After the third session, participants received the draft report for the second round of review and member checking before the report was finalized. Through holding multiple consultation sessions, receiving additional comment between sessions, and multiple rounds of member checking analysis and reports, data saturation was reached.

Data analysis. Data were analyzed using an inductive thematic analysis approach (10,11). Two authors (TDB and LW) reviewed the video recording, text-based chat, and field notes after sessions 2 and 3 and separately analyzed the data for recurrent themes. The separate analyses were compared, and the authors discussed the identified themes until consensus was reached. Population groups particularly affected by each indirect impact theme and potential outcomes of the impacts were also drawn from the analysis. Illustrative quotes were selected to demonstrate critical issues. The participants received 2 versions of the draft report to review and refine via email (see "data collection" above).

Ethical considerations. This consultation was a quality assurance activity conducted for the primary purpose of improving service provision in NSW Health by gathering experiential evidence from consumer and community members. Experiential evidence describes the knowledge, expertise, and wisdom that individuals or groups develop from encounters, involvement, or practice. It is generally sought in relation to "real-world" situations or experiences, for example, living with or treating a particular illness or condition, familiarity with a setting or context, or belonging to a social or professional group.

As a quality assurance activity, ethical review was not required as per the National Health and Medical Research Council, Ethical Considerations in Quality Assurance and Evaluation Activities guidance (12), and the NSW Health Quality Improvement and Ethical Review: A Practice Guide for NSW (13). Partnering with consumers in governance, policy, and planning is recognized best practice, and this

consultation aligned to the National Safety and Quality Health Services Standards in Australia (14). Participants voluntarily responded to the invitation to participate in the group discussions, received an information pack with background information, and provided informed consent.

Results

Virtual discussions occurred between August 24 and August 31, 2020 with 33 consumer and community members in NSW. Two groups formed based on the availability and preferences of participants; 1 group with 21 participants and 12 participants in the second group.

The 3 main themes identified through the analysis are poor health outcomes for individuals; problems with how health care is designed and delivered; and increasing health inequity. Twelve subthemes were identified within the 3 main themes. The full list of 12 subthemes, presented in descending order of priority identified by participants, along with affected population groups and potential outcomes, are shown in Table 1.

Poor Health Outcomes for Individuals

Mental health issues and suicide risks. The majority of participants were concerned about the development of new mental health conditions, exacerbation of existing conditions, mental health crises, and increased risk of suicide. A range of contributing factors were identified, including social isolation and disconnection from usual support networks, an inability to participate in regular social events, people and families constrained in challenging and unsafe home environments due to restrictions on movement, and canceled or limited access to usual mental health services.

> One woman living alone in a block of units with anxiety, which she manages well, detailed how the impact of isolation with other neighbours and their noise levels increased her anxiety to a level that she required further support from the community mental health team. Normally the other neighbours would be out most of the day but with lockdown, the fact they were indoors and trying to manage the boredom through loud music. This increased incidents of neighbour disputes, conflict and mental health episodes.

A small number of participants also highlighted the increased risk of poorer mental health for people who do not speak English. Difficulty in organizing telephone interpreters and a lack of translated and Easy English information about services were identified as barriers.

Outpatient and community-based health services. Participants raised issues with reduced, canceled, rescheduled, and delayed access to a wide range of outpatient hospital and community-based services. This included general practitioners, specialist services, allied health services, dental appointments, immunization services, mental health services, exercise rehabilitation, drug and alcohol services, in-home respite services, and other home-visiting disability- and aged care-services, screening and diagnostic services, patient support groups, in vitro fertilization treatment, women's health, and carer supports.

> My grandmother who is recovering from cancer. She is meant to have 3-monthly checks up. The appointment in March was cancelled because of COVID, it got cancelled again in April, and in May. They went to cancel it again in June and I put my foot down. The difference between 3 monthly check ups and now 7 months, it could come back and the chances of it being worse are much higher.

Many participants also noted how canceled and postponed appointments have pushed outpatient waitlists out even further:

> On a 9-month waitlist for a development assessment for a young person showing signs of autism. The appointment was then cancelled because of COVID-19 and this happened 3 months in a row. A behavioural assessment was then conducted over the phone and it wasn't effective. This has a lot delayed early intervention.

Participants also described how some services had canceled regular face-to-face appointments for people with chronic disease to minimize the risk of COVID-19 transmission when attending the service. Other participants were avoiding attending face-to-face appointments because they were worried about contracting COVID-19. This meant that some people with chronic conditions were missing out on being physically seen as regularly as usual and were also sometimes reluctant to tell health care workers when they were becoming unwell.

> I am slowly slipping backwards when I have come so far. Over the time of isolation—pain has increased and on occasions this has resulted in an increase use of medication for treatment.

Domestic and family violence. Participants were concerned about an increase in domestic and family violence and sexual assault in the home. Stress, job losses, restrictions on movement, and loss of access to formal and informal supports were identified as factors increasing risk.

Population health. Participants believed that COVID-19 restrictions on movement and an increase in people working from home may increase noncommunicable diseases due to a reduction in physical activity, weight gain, and poor ergonomic setup of workspaces. This was a particular concern for people with existing conditions or complex care needs because reduced physical activity and increased weight can impact function, worsen symptoms, and increase care needs.

Participants also felt that changes in routine and restrictions on movement and social connectedness could lead to

Table 1. Indirect Impacts Ranked Subthemes Arising From NSW Health Consultation.

Rank	Subthemes	Population groups affected	Potential outcomes
1	Mental health issues and suicide risks	While this list should not be considered exhaustive, groups identified through this consultation as particularly vulnerable to mental health impacts include • Young people • Older people • People with existing lived experience of mental health conditions and issues • People from culturally and linguistically diverse backgrounds, including refugees, asylum seekers, and international students • Aboriginal and Torres Strait Islander people • Health care workers • Carers • LGBTIQ+ people	• Increased rates of suicide, suicide attempts, and self-harm • Increased mental health crisis presentations to emergency departments • Changed rates, frequency, and timeliness of access to mental health services, including telephone services (eg, increased referrals, reduced availability of services, and delays in access leading to more acute presentations) • Increased workforce impacts with health care workers experiencing high stress and burnout (eg, reduced staffing levels and reduced quality of care)
2	Outpatient and community-based services	• People with chronic conditions (eg, chronic pain, cancer, COPD) • People undergoing treatment which requires regular contact with health services or providers (eg, people with cancer, people undergoing transition) • People with rare/undiagnosed conditions going through the process of seeking a diagnosis • Older people and people living with frailty • Children • People with drug and/or alcohol dependence	• Delayed diagnosis/detection of disease leading to people presenting with more advanced stages of disease and illness and restricting options for effective treatment/management • Delayed, or decreased likelihood of, recovery • Worsening symptoms of chronic conditions • Increased use of pain medication • Decreased function, sometimes impacting on the ability to be safe and remain at home • Increased waitlists for outpatient services
3	Consumer engagement and patient experience	• Consumer representatives • Health services • Consumers, patients, and their families	• Decreased person-centeredness • Reduced ability for health services to meet requirements under the National Safety and Quality in Health Care Standards—Partnering with Consumers • Delayed quality improvement and service design projects that are responding to complex health system issues
4	Communication with communities	• Aboriginal and Torres Strait Islander people • Culturally and linguistically diverse communities, particularly people with low English proficiency and/or literacy • People with intellectual disability • People with low computer literacy and/or no way to access online information (eg, no internet access, computer, smartphone) • People with hearing impairments	• Increased inequities in vulnerable communities when communication (content and delivery method) is not tailored for communities • Decreased person-centered care communication (with impacts on making treatment options/decisions) as a result of mask-wearing in health settings
5	Telehealth	**Benefits** • People with chronic disease and/or disability • Regular users of the health system • Carers who find it difficult to leave their home due to caring responsibilities **Risks** • People with chronic and/or complex conditions, particularly those requiring regular monitoring/testing that can't be conducted remotely • People from non-English speaking backgrounds who require interpreters to communicate with health professionals • Aboriginal and Torres Strait Islander people • People with low computer literacy and/or no way to access online services (eg, no internet access, computer, smartphone) • People living in regional, rural, and remote areas • People from socioeconomically disadvantaged communities	**Benefits** • Improved access to care • Lower out-of-pocket health care costs relating to travel, parking, etc **Risks** • Reduced access to health care • Compromised shared decision making when carers/family members are unable to join the call to support consumers to understand health choices and make health care related decisions

Table 1. (continued)

Rank	Subthemes	Population groups affected	Potential outcomes
6	Vulnerable communities	• Young people, particularly those in foster care or the juvenile justice system • Culturally and linguistically diverse communities, particularly refugees, asylum seekers, international students, and anyone on a temporary visa • Aboriginal and Torres Strait Islander people • People experiencing homelessness • Older people	• Reduced access to health care • Untreated health conditions
7	Domestic and family violence	• Women • Children and young people • LGBTIQ young people	• Increased rates of domestic and family violence • Increased rates of sexual assault • Increased physical and mental health care needs resulting from violence and trauma • Increased rates of births resulting from coercion
8	Visitor restrictions	• Patients in palliative or end-of-life care and their families • Residents in aged care and their families • Family members of people having surgery, particularly when the condition is life-threatening • People with communication disabilities and impairments (eg, people who are nonverbal) who rely on family members or carers to interpret their communication on communicate on their behalf • Parents and children, particularly when parents are unable to stay overnight in hospitals and/or when complex diagnostic and treatment decisions are being made for children and both parents are not allowed to be present at the same time • People with complex conditions and care needs who benefit from family members/carers being present to assist health-related decision making • Families during birth and inpatient postnatal stay • Families of people in inpatient facilities	• Increased risk of trauma for patients and family members who are unable to be together in significant times in people's lives (including birth and death) • Compromised shared decision making when carers/family members are not present to support patients understand health choices and to make health care related decisions
9	Cross border access to health care	• Border communities • Aboriginal people	• Reduced access to health care • Increased rates of mental health impacts for consumers and their families due to not being able to stay with/visit loved ones in hospital • Increased rates of mental health impacts due to isolation from family, friends, communities, and support networks outside of home state
10	Population health	• People working from home • People with chronic conditions and/or complex care needs • People who use alcohol and other drugs • Carers	• Increased chronic conditions related to reduction in physical activity and increase in weight (eg, musculoskeletal conditions, diabetes) • Increased rate of occupational injuries (eg, overuse injuries, headaches and eye strain) • Increased care needs for people requiring in-home care services • Worsened symptoms and loss of function for people with chronic disease • Increased rate of overdose and other health problems for people who use drugs
11	Moving through the health system	• Inpatients • People moving between health services (eg, transitioning from acute care to rehabilitation)	• Decreased continuity of care, leading to poorer health outcomes • Decreased patient experience of receiving health care
12	The future of health care	• People with chronic illness and/or disability who rely on private services providers for in-home care	• Decreased access to care services • Increased out-of-pocket costs for patients/clients • Increased use of public services

Abbreviation: LGBTIQA, lesbian, gay, bisexual, transgender, gender diverse, intersex, queer, asexual and questioning communities; NSW, New South Wales.

changes in how people use drugs, increasing the risk of increased use or overdose.

Problems With How Health Care Is Designed and Delivered

Consumer engagement and patient experience. Some participants indicated that consumer engagement activities were put on hold for many services in response to COVID-19. Where consumer engagement was occurring, it was often COVID-19 focused and other important service change and quality improvement activities were canceled. Where consumer engagement was happening, it was conducted remotely via technology, and consumer representatives with low computer literacy or no access to devices or internet were unable to contribute.

Telehealth. Participants raised both benefits and risks associated with the rapid implementation of telehealth in response to COVID-19. The use of telehealth and e-prescriptions had improved access to health care for some community groups, particularly in terms of reduced travel times and costs associated with attending face-to-face appointments.

However, some people noted that the availability of telehealth was not consistent across health services and had yet to be embedded as routine clinical practice. It was also noted that telehealth is not always suitable, particularly when physical tests are required as part of health appointments.

People from non-English-speaking backgrounds, those in areas of poor internet or telephone coverage, or people who are unable to afford access to digital services, were identified as particularly at risk of missing out on telehealth services.

> Even though interpreting services are available, it is quite difficult to translate or understand some technical terms over the phone.

Visitor restrictions. Participants were concerned with visitor restrictions being implemented inconsistently across health systems in NSW. The restrictions tended to privilege infection control concerns and did not always balance how a lack of family presence can negatively impact on a person's health outcomes. Information for patients, carers, and families about visiting policies were not readily available.

> Relatives of terminally ill or those in aged care facilities are very distressed. Some are expressing they won't accept palliative care facilities due to restrictions however very concerned about how they are going to cope with end of life care.

Cross border access to health care. Some states and territories in Australia implemented border restrictions and closures in response to COVID-19. The border restrictions and closures impacted access to health care, and social and emotional well-being for people living close to state borders. Informal supports—such as relatives providing support and assistance to patients post-discharge—were also impacted by restrictions to movement across state borders.

> Restrictions on travel and quarantine were not developed with the needs of regular users of health services in mind. This is impacting on people living in one state and receiving care in another.

Moving through the health system. Some participants shared that wait times to move from the emergency department to the ward increased in some hospital settings. Patients were also sent to other hospitals because of limited beds and wards being rearranged to accommodate COVID-19 cases. Transport of patients between hospitals has been via ambulance, and some patients were unable to have family support during the transition between services.

Future of health care. Participants were concerned about the financial and staffing impacts for some private and nongovernment organizations and how this might impact the availability of services into the future.

Increasing Health Inequity

Communication with communities. The majority of participants expressed that the information shared by hospitals, health services, and the government about COVID-19 and service changes was poor. Information about COVID-19 was rarely in accessible formats including Easy English and translated materials.

Public messaging often focused on prevention of transmission for people who were well but did not help people who were regular users of the health system and having to maintain their health and navigate health systems during COVID-19. Participants perceived that communications were often slow to reach the communities who needed it, and there was an inconsistency between public health officials, government websites, and the media.

Vulnerable communities. Participants raised concern for specific vulnerable communities at increased risk during the pandemic. This included young people in care (eg, foster care and kinship care), young people from refugee and migrant backgrounds with limited language skills, and people in Australia on temporary visas who may face increased costs and problems accessing health care.

Discussion

The COVID-19 pandemic has had a profound impact on us all. In NSW, where the prevalence of infections has been relatively low, people have been most affected by public health measures such as lockdowns and physical distancing. This includes those with unmet health care needs either due to a lack of availability of services or a

reluctance to present for care because of concerns about COVID-19 and infection risks.

There can be no doubt that even people with no direct experience of COVID-19 infection have had their lives, and potentially their health, disrupted. The key questions are what to do about these indirect impacts, and how do we track them as they emerge and evolve? Additionally, how do we develop these responses in partnership with health consumers and communities?

Health systems continue to explore new, COVID-safe, ways to facilitate consumer engagement activities through responding to physical distancing requirements and gathering limits for indoor spaces and taking advantage of virtual technologies. Partnering with health consumers and community members is essential in responding to the indirect impacts of COVID-19 and in the recovery phase of the pandemic. Using codesign methods may help to manage power structures and ensure the representation of people with lived experience is occurring beyond tokenistic involvement (15,16). An investment in codesign preparedness is required (15), along with the allocation of both human and material resources to support engagement efforts (14,17,18).

The disruption of COVID-19 provides a window of opportunity to change entrenched ways of working and address wicked problems such as mental health issues and the social determinants of health. Wicked problems are conceptually complex and can be best addressed by drawing on lived experience knowledge as a form of experiential evidence, alongside research and empirical evidence (19).

There were 2 main limitations of the study. The first is that the participant group was self-selected. Although participants had broad-ranging background and interests the group may not be representative of a full range of health care experiences. Additionally, participants self-selected into the discussion groups, leading to unequal numbers in each group. This may have meant that some participants had difficulty fully contributing to the discussions, particularly in the larger group. However, the consultation approaches of having multiple discussions, receiving additional comments between sessions, member checking each stage of the analysis and report, and collecting discussion session data through both video recording and text chat were aimed at ensuring all participants had the opportunity to contribute their experiences and views to the data collection, even if their participation in the verbal discussion was limited.

Secondly, the work reflects views at a single time point, in one geographic location, in an international situation that is rapidly evolving and changing as the pandemic unfolds. Therefore, this work must be ongoing in NSW to gauge changes in perspectives and track other indirect impacts as they emerge over time, and other jurisdictions must conduct their own consultations to understand the unique impacts facing their health consumers and communities.

Conclusion

This study provides insight into the indirect impacts of COVID-19—even in settings with a relatively low number of COVID-19 positive cases. It provides evidence and important insights directly from health care consumers and community members and can be used to inform health system responses in the recovery phase of the COVID-19 pandemic.

Authors' Note

This consultation was a quality assurance activity conducted for the primary purpose of improving service provision in NSW Health. As a quality assurance activity, ethical review was not required by following the National Health and Medical Research Council, Ethical Considerations in Quality Assurance and Evaluation Activities and the NSW Health Quality Improvement and Ethical Review: A Practice Guide for NSW. Partnering with consumers in governance, policy and planning is recognized best practice, and this consultation aligned to the National Safety and Quality Health Services Standards in Australia.

This quality improvement activity was judged as low risk by our governance committees and there were no triggers for ethical review flagged during the planning and review of the project. Oversight was provided through the structures of the NSW Health CIU and the Agency for Clinical Innovation, an organisation benefitting from a permanent Audit and Risk Management Committee as well as a Research and Education Subcommittee of the Board. As part of the work of the CIU, this project was assessed by the Clinical Advisory Group which includes members from a number of academic institutions with many years of experience leading quality improvement, evaluation and research. Participants voluntarily responded to the invitation to participate in the group discussions, received an information pack with background information and provided informed consent.

Declaration of Conflicting Interests

Funding

ORCID iD

Tara Dimopoulos-Bick ⬤ https://orcid.org/0000-0002-5007-8557

References

1. Rutter MD, Brookes M, Lee TJ, Rogers P, Sharp L. Impact of the COVID-19 pandemic on UK endoscopic activity and cancer detection: a national endoscopy database analysis. Gut. 2020:70:537-543. gutjnl-2020-322179.

2. Sud A, Jones ME, Broggio J, Loveday C, Torr B, Garrett A, et al. Collateral damage: the impact on outcomes from cancer surgery of the COVID-19 pandemic. Ann Oncol. 2020;31: 1065-74.

3. Montaner J, Barragán-Prieto A, Pérez-Sánchez S, Escudero-Martínez I, Moniche F, Sánchez-Miura JA, et al. Break in the stroke chain of survival due to COVID-19. Stroke. 2020;51:2307-14.

4. Mafham MM, Spata E, Goldacre R, Gair D, Curnow P, Bray M, et al. COVID-19 pandemic and admission rates for and management of acute coronary syndromes in England. Lancet. 2020;396:381-9.

5. Pierce M, Hope H, Ford T, Hatch S, Hotopf M, John A, et al. Mental health before and during the COVID-19 pandemic: a longitudinal probability sample survey of the UK population. Lancet Psychiatry. 2020;7:883-92.

6. Newby JM, O'Moore K, Tang S, Christensen H, Faasse K. Acute mental health responses during the COVID-19 pandemic in Australia. PLoS One. 2020;15:e0236562.

7. Narici M, De Vito G, Franchi M, Paoli A, Moro T, Marcolin G, et al. Impact of sedentarism due to the COVID-19 home confinement on neuromuscular, cardiovascular and metabolic health: physiological and pathophysiological implications and recommendations for physical and nutritional countermeasures. Eur J Sport Sci. 2020:1-22.

8. Moynihan R, Sanders S, Michaleff ZA, Scott A, Clark J, To EJ, et al. Pandemic impacts on healthcare utilisation: a systematic review. medRxiv. 2020:2020.10.26.20219352.

9. Innovation AfC. COVID-19 Critical Intelligence Unit agency for clinical innovation. 2020. Retrieved October 30, 2020, from: https://www.aci.health.nsw.gov.au/covid-19/critical-intelligence-unit

10. Braun V, Clarke V.Thematic analysis. APA handbook of research methods in psychology, Vol 2: research designs: quantitative, qualitative, neuropsychological, and biological. In: APA Handbooks in Psychology®. American Psychological Association; 2012:57-71.

11. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3:77-101.

12. Council NHaMR. Ethical considerations in quality assurance and evaluation activities. In: Government A, ed. National Health and Medical Research and Evaluation Activities. NHMRC; 2014.

13. Research OfHaM. Research – ethical & scientific review of human research in NSW public health organisations. In: Health N, ed. 2010.

14. Care ACoSaQiH. Partnering with consumers standard. 2017. Retrieved October 30, 2020, from: https://www.safetyandquality.gov.au/

15. Dimopoulos-Bick T, O'Connor C, Montgomery J, Szanto T, Fisher M, Sutherland V, et al. "Anyone can co-design?": A case study synthesis of six experience-based co-design (EBCD) projects for healthcare systems improvement in New South Wales, Australia. Patient Exper J. 2019;6:93-104.

16. Palmer JV, Weavell W, Callander R, Piper D, Richard L, Maher L, et al. The participatory zeitgeist: an explanatory theoretical model of change in an era of coproduction and codesign in healthcare improvement. BMJ. 2019;45:247-57. Epub 2018.

17. NSW HC. COVID-19 resource hub. 2020. Retrieved October 29, 2020, from: https://www.hcnsw.org.au/covid-19-resource-hub/

18. Heath S. How will COVID-19 change patient experience, healthcare delivery? 2020. Patient Satisfaction News. https://patientengagementhit.com/news/how-will-covid-19-change-patient-experience-healthcare-delivery.

19. Signal LN, Walton MD, Ni Mhurchu C, Maddison R, Bowers SG, Carter KN, et al. Tackling 'wicked' health promotion problems: a New Zealand case study. Health Promot Int. 2012;28:84-94.

Author Biographies

Tara Dimopoulos-Bick is the Evidence Generation and Dissemination Manager – Experiential Evidence at the NSW Agency for Clinical Innovation (ACI) and she has a Social Work background. Tara's work focuses on bringing the knowledge, expertise and wisdom from individuals and groups to the forefront as part of the ACI's evidence model. Her interests include participatory research methods and positioning patient experience as a form of evidence.

Louisa Walsh is a PhD student at La Trobe University, with a background in physiotherapy and health communications. She is also a person with a life-long chronic illness and has worked in numerous consumer representative roles in hospitals and other health organisations. Her research interests include the use of social media for consumer engagement in health, participatory research methods, electronic health records, and quality improvement in health services.

Kim Sutherland leads the Evidence Directorate of the NSW Agency for Clinical Innovation. Her career has spanned health services research internationally and senior management roles in healthcare organisations. Kim's work focuses on quality of health care, the translation of evidence into clinical practice, performance measurement and reporting, and unwarranted clinical variation.