

Rapid evidence checks are based on a simplified review method and may not be entirely exhaustive, but aim to provide a balanced assessment of what is already known about a specific problem or issue. This brief has not been peer-reviewed and should not be a substitute for individual clinical judgement, nor is it an endorsed position of NSW Health.

Preserving consumer and patient partnership during COVID-19

Rapid review question

How can we preserve consumer and patient partnership approaches during COVID-19? Specifically, what guidance is available for patient experience and person-centred care in renal care?

In brief

- In response to the COVID-19 pandemic, organisations are using initiatives and programs to preserve patient experience and person-centred care.
 - NSW Health is expanding the 'Patient Experience Program' to COVID-19 clinics. This initiative involves four key strategies: patient experience officers, information technology, waiting room enhancements and staff support and development.
 - The Point of Care Foundation in the UK has implemented 'Team Time'; online reflective practice sessions for health professionals to share experiences of their work in health and social care.
 - Patient partnership champions have called for the immediate recognition of families as 'essential partners in care' not 'visitors' in response to COVID-19 visitor policies. The Beryl Institute further suggests the need to reinstate responsible access and visitation policies that balance clinical and personal needs.
 - Hospitals are using virtual visiting solutions, apps and smart devices to support communication between patients and families.
 - McMaster University and the National Hospice and Palliative Care Organisation have developed patient decision aids to support shared decision making during COVID-19.
- A May 2020 Beryl Institute survey on US patient experience in healthcare found despite lower engagement in healthcare activities in the context of COVID-19, consumers were more positive about overall healthcare quality and their own care experiences compared to the previous survey in January 2020.
- Evidence based guidance on the introduction and use of video consultations during COVID-19 notes that technology can alter the quality of clinical encounters and outcomes. Expert opinion is that video consultation is preferable to telephone as it supports relationship building and allows patients to feel more comfortable.
- Australia's Health Panel asked 95 panellists about their views and perceptions on the use of telehealth in Australia during March 2020. Only one third (n=32) had ever been offered a

telehealth service and the majority found it to be of excellent or good quality. When compared to regular face-to-face consultations; 11 panellists believed it was better than face-to-face, 9 thought it was worse and 8 thought it was more or less the same.

- In renal care during COVID-19, opinion recommends transparency when disclosing information to patients in dialysis units. This includes communicating what patients can and cannot expect from the service during COVID-19.
- Broader evidence base for renal care.
 - A systematic review found person-centred integrated care may have little effect on mortality or quality of life.
 - Evidence from a number of studies suggests patient education and shared decision making can help achieve person-centred care for people with chronic kidney diseases.
 - Expert opinion suggests a collaborative approach, using shared goals rather than prescribed targets, a greater understanding by the individual of their condition and their treatment can lead to better decision-making and a more positive experience of care.

Limitations

- There is limited evidence and guidance available on preserving patient experience and person-centred care during COVID-19. Where available, the quality of evidence is low.
- There are ongoing debates around definitions and terminology. Consumer and patient are used in this review to acknowledge people accessing healthcare have individual preferences.
- Recommendations are copied from source material and no attempt has been made to integrate the different guidance. There is likely to be additional evidence, guidance and resources not included in this rapid review.
- The scope of the review did not include specific COVID-19 resources developed by and/or for patients and consumers.
- The review did not address enhanced engagement strategies, which may be required for priority population such as Aboriginal and Torres Strait Islander people, older people or people living in regional and remote areas.
- This is a rapid evidence review that has not been developed with and/or reviewed by patients or consumers.

Background

Person-centred care encompasses four distinct principles: 1 care is delivered with dignity, compassion, and respect; 2 care is well coordinated; 3 care is personalised taking into account clinical, social, emotional, and practical needs; and 4 care enables people to take an active role in their own care. Person-centred care includes shared decision-making; however, it can go beyond this to include full coproduction health partnerships, where consumers, patients, carers, and their healthcare team work together as equal partners to influence health service design, service delivery, and service evaluation. (1-3)

The Beryl Institute has defined patient experience as the ‘sum of all interactions shared by an organisation’s culture that influence patient perceptions across the continuum of care’. They released the framework for the *Future of Human Experience 2030*, which includes eight elements: culture and leadership; infrastructure and governance; staff and provider engagement; policy and measurement; environment and hospitality; innovation and technology; patient, family and community engagement; and quality and clinical excellence. (4)

Patient experience is one part of the ‘triple aim’ along with improving population health and reducing costs. The triple aim was introduced by the US-based Institute for Healthcare Improvement; and is

defined as an approach to optimise health system performance. Organisations are extending it to the 'quadruple aim' to include staff and provider experience.(5)

There is emerging evidence that indicates better patient experience may be associated with improved outcomes in clinical effectiveness and safety. Similarly positive effects have been shown from interventions of person centred care in terms of self-rated health, well-being and quality of care in a small number of studies. Systematic reviews indicate that more stringent studies are required however to determine the evidence base. (6,7)

In Australia, the National Safety and Quality Health Service (NSQHS) *Partnering with Consumers Standard* is a formal structure and accountability mechanism for involving consumers and patients as partners in their own care and in planning, design, delivery and evaluation of systems and services.(8)

Helping people make informed choices and maintain healthy behaviours requires a partnership approach between patients, consumers and health professionals. The NSW Agency for Clinical Innovation has a consumer enablement guide to support patients and consumers to be active partners in their own healthcare.

Methods (Appendix 1)

Searched PubMed, grey literature and Twitter on 20, 21 and 22 May 2020.

Results (Tables 1-3)

Table 1: Preserving patient experience and person-centred care during COVID-19

Source	Advice
Peer reviewed sources	
<p>Family-centered care during the COVID-19 Era Hart, et al. 2020 (9)</p>	<ul style="list-style-type: none"> • Health systems must rapidly adapt family-centric procedures and tools to circumvent restrictions on physical presence. Internet-based solutions can facilitate the routine, predictable, and structured communication, which is central to family-centred care. • Establish a communication plan with the patient and family members shortly after admission or transfer within the hospital. • Encourage patient and family to call, text, and videoconference with one another using their preferred methods as often as desired. • Create a system to have limited personal effects delivered to patients’ room such as children’s art, sports memorabilia, or religious items. • Ask family members to describe the patient’s past times and life story, including important people in their life, to facilitate conversation between the clinical team and the patient.
<p>Community participation is crucial in a pandemic Marston, et al. 2020 (10)</p>	<ul style="list-style-type: none"> • Community participation is essential in the collective response to COVID-19, from compliance with lockdown, to the steps that need to be taken as countries ease restrictions, to community support through volunteering.

Source	Advice
<p>Guidance on the introduction and use of video consultations during COVID-19: important lessons from qualitative research</p> <p>Wherton, et al. 2020 (11)</p>	<ul style="list-style-type: none"> • Video is playing an increasingly important role in providing patients with access to healthcare, either for those with COVID-19 symptoms or with other conditions. In many cases, patients suspected of COVID-19 present with mild symptoms and are mainly seeking advice and reassurance, which can often be provided by telephone. However, video may be more appropriate for sicker patients, more anxious ones and those with comorbidities, as it would provide additional visual information, diagnostic clues and therapeutic presence. • There are subtle ways in which the technology can alter the dynamic between the patient and clinician, and so additional interactional work is required. <ul style="list-style-type: none"> ○ Setting up: checking that the video and audio is working well and instructing the patient to help improve quality if needed (e.g. unmuting the microphone and switching on the video camera). ○ Social talk: non-clinical talk to support rapport building and putting the patient at ease, including greetings and providing reassurance. ○ Clinical talk: information related to the patient’s condition or illness, treatment and management. Summarise the key points at the end of consultation to check key information had been clearly communicated. ○ Repair talk: correcting significant disruption to the flow of the consultation due to latency or technical breakdowns (e.g. pausing and inviting the patient to continue talking when overlap or interruption occurs). ○ Operational talk: instructing and guiding the patient to support the consultation. This may include requests to improve the quality of the consultation (e.g. asking the patient to speak louder and reposition the webcam) or during physical examinations (e.g. position the camera or change the lighting to get a better view).
<p>Covid-19: a remote assessment in primary care</p> <p>Greenhalgh, et al. 2020 (12)</p>	<ul style="list-style-type: none"> • Guiding principles on how to choose between telephone and video appointments, how to conduct a ‘query covid’ consultation remotely and considerations when arranging follow-up and next steps. • Although such consultations can be done by telephone in many cases, video provides additional visual cues and therapeutic presence.

Source	Advice
<p>Capturing patient-reported outcomes during the COVID-19 pandemic: development of the COVID-19 Global Rheumatology Alliance patient experience survey</p> <p>Sirocich, et al. 2020 (2)</p>	<ul style="list-style-type: none"> Community members had unique concerns related to their disease and treatment. These included whether their rheumatic disease or immunosuppressive treatments increased their risk of COVID-19 infection, or of poor outcomes should they become infected, if changes to their medications were desirable, and if their ability to obtain their medications would be impaired, as rheumatic disease drugs were being used to treat COVID-19. To answer these questions and expand upon the rheumatology community’s understanding of the impact of the COVID-19 pandemic on people with rheumatic disease, the C19-GRA launched the patient experience survey.
<p>Coronavirus (COVID -19): patient experience – administrative services on the frontline during crisis</p> <p>Overton, et al. 2020 (13)</p>	<ul style="list-style-type: none"> The Cancer Center, MD Anderson, Division of Patient Experience, played an integral role in the institution's pandemic response which included: enhanced vigilance and compassionate care; clear, concise and thorough communication; technology-based creative solutions; triaging surgeries and access to care; and advancing use of advanced care plans.

Source	Advice
<p>Pandemic uncertainty: considerations for nephrology nurses Harwood 2020 (15)</p>	<ul style="list-style-type: none"> • Pandemics are extreme situations that are ripe with uncertainty. Acknowledging that this uncertainty is universal in a pandemic for patients, staff, and leaders is important in understanding individual behaviours and actions, reactions, or inaction among some. Using problem rather than emotion-focused problem-solving, communicating with transparency to instil trust, aiming to be agile in responses to situations, and keeping mindful of 'the greater good' may assist nephrology nurses in ameliorating the uncertainty. • Transparency should be included when disclosing information to patients in dialysis units. This includes being honest regarding the situation in the unit and how patients can help protect themselves, their health care providers, and their family members. It is important to communicate what they can and cannot expect from services. • Dialysis units may have an advantage because there may already be trusting therapeutic relationships developed between nurses and patients, and patients may be more likely have trust in healthcare advice and the managing of the situation to mitigate risk. This also includes that nurses have trust in their unit leadership, despite the frequent and rapid changes.
<p>Quantifying the impact of COVID-19 on cancer patients: a technical report of patient experience during the COVID-19 pandemic at a high-volume radiation oncology proton center in New York City Press, et al. 2020 (16)</p>	<ul style="list-style-type: none"> • This study report describes the institutional patient experience and quantifies the impact of treatment delays and interruptions over the first month of the COVID-19 outbreak.

Source	Advice
Grey literature	
<p>Consumer perspectives on patient experience in the U.S.</p> <p>The Beryl Institute 2020 (17)</p>	<ul style="list-style-type: none"> • The Beryl Institute and Ipsos PX Pulse conducted their quarterly survey to track current perspectives on patient experience in healthcare across the United States; amidst the COVID-19 pandemic. • Despite lower engagement in healthcare activities and the spread of COVID-19, consumers are more positive about overall healthcare quality (+13%) and their own care experiences (+7%) compared to the last quarter in January 2020 • Reducing the threat of infectious diseases (+7%), communication with patients/families (+6%), and quality of hospital care (+5%) emerged as issues more important to consumers this quarter compared to the last quarter in January 2020.
<p>Supporting person-centred care in COVID-19 situations</p> <p>Healthcare Improvement Scotland 2020 (18)</p>	<ul style="list-style-type: none"> • Designated hashtag to share resources #C19carescot • Collated a list of examples of compassionate care that are already being used by health and social care staff in Scotland. <ul style="list-style-type: none"> ○ Connecting patients with their loved ones ○ Connecting colleagues to support wellbeing ○ Connecting staff with patients relatives ○ Maintaining therapeutic relationships ○ Caring for children during COVID-19 ○ Caring for those with additional needs.

Source	Advice
<p>Making remote consultations work for patients during covid-19: experience from the “other side” of the virtual clinic Giles, et al. 2020 (19)</p>	<ul style="list-style-type: none"> • Scheduling an appointment requires clear contact information, processes, and expectation management. • Once the appointment has been secured, without careful consideration there is a chance that virtual processes can replicate the worst elements of in-person appointments. • Having access to the internet may also be difficult for those on low incomes or older people who do not routinely use technology. • Difficulties in privacy and internet access aside, our general impression is that in many cases a video consultation is preferable to telephone. It allows clinicians and patients to see one another, for patients to show areas of concern to their doctors, and for doctors to assist patients in self-exams. Where patients and doctors have a pre-existing relationship, video calls allow for relationships to be reinforced. For new consultations, video supports the building of a trusting relationship and allows patients to feel more comfortable discussing personal issues. • Tips for video and telephone consultations. <ul style="list-style-type: none"> ○ Be clear about how long an appointment is likely to take, who it is with, and what will be discussed. ○ Take time to acknowledge the pandemic and how appointments have changed. Ask how patients have been affected by lockdown and isolation. ○ Not everyone will be able to access a quiet, well-lit space with a good internet connection. Consider what the minimum for an effective consultation might be. ○ Be clear about next steps for treatment and management, particularly in the current context. ○ Discuss potential impacts, if any, on delays to treatment, scans or other clinical appointments.
<p>A pandemic lesson: the importance of person-centered care Chernof 2020 (20)</p>	<ul style="list-style-type: none"> • When a person’s values and preferences are elicited and a plan of care is put in place based on those values and preferences, health plans and their medical providers are better positioned to serve that person’s needs, particularly during crises. • Examples of health systems implementing new strategies include increase use of telehealth.

Source	Advice
<p>Improving patient experience in NSW NSW Ministry of Health 2020 (21)</p>	<ul style="list-style-type: none"> • NSW Health is expanding its Patient Experience program to emergency departments and newly established COVID-19 clinics. • The program aims to make sure people: <ul style="list-style-type: none"> ○ know where to go when they arrive ○ are communicated with in a caring manner ○ know what to expect during their time in the emergency department ○ have access to water, refreshments and free wi-fi ○ can keep key communication devices charged while waiting ○ are provided with information regarding emergency department processes ○ have information in their language ○ are updated on when they are likely to be seen, the status of test results and any delays.
<p>Reasons for optimism in experience of care Cornwell 2020 (22)</p>	<ul style="list-style-type: none"> • The changes made in respond to COVID-19 are real and systemic; they have come from the centre, but they are making an impact on every NHS organisation and changing the work of delivering patient care.
<p>Team time Point of Care Foundation 2020 (23)</p>	<ul style="list-style-type: none"> • Team Time is a 45-minute reflective practice session that is run and facilitated online and provides an opportunity to share experiences of work in health and social care. As with Schwartz Rounds the focus is on participants’ emotional and social response to their work. However, unlike Schwartz Rounds, the audience is limited in size and is intended to be drawn from an area or department of a health or social care site rather than from across the organisation. The audience will comprise colleagues who have common cause with others in a specialty or pathway and consider each other colleagues in the work of that area.

Source	Advice
<p>In this time of COVID-19 there should be more, not less caregiver partnership Drury, et al. 2020 (24)</p>	<ul style="list-style-type: none"> • Immediate recognition of the difference between visitors and family caregivers as ‘essential partners in care’. • Collaboration on an immediate reintegration strategy for family caregiver presence that is based on a triage methodology. This includes: <ul style="list-style-type: none"> ○ identifying specific high risk and high needs patient and resident groups ○ allowing for applications for exemptions to any family caregiver and visitor policy ○ a review committee for these exemptions (which family and caregivers are a part of) ○ appropriate screening, information and PPE (when available for 1-2 identified family caregivers as essential partners in care). • Assurance that where family caregiver presence is not physically possible, essential partners in care are offered virtual means to connect to either daily rounds with the clinical team and/or a daily update about the status of the patient. • Assurance that all patients will be supported with access to technology, e.g. tablet, mobile phone, email, etc. in order to stay connected with family caregivers and that access to this technology will not be restricted unnecessarily and will be supported by the institution. • Immediate and continual reassessment of visitor policies and emerging reintegration strategies and family presence policies with caregivers, patients and families as the COVID-19 situation changes.

Source	Advice
<p>Leading and driving change from bedside to the board during Covid-19 O’Conner 2020 (25)</p>	<ul style="list-style-type: none"> • Questions may help identify changes required to improve patient care, the environment and staff wellbeing during COVID-19. <ul style="list-style-type: none"> ○ What went well yesterday? ○ What is going well today? ○ Things that could be better? ○ How are you feeling? ○ Changes we have made? ○ Anything you need or need help with?
<p>Resources and connections to support our community in addressing COVID-19 The Beryl Institute 2020 (26)</p>	<ul style="list-style-type: none"> • Community briefings with chat notes. Points include: <ul style="list-style-type: none"> ○ visitation policies ○ humanistic connection while safe physical boundaries ○ health literacy ○ compassionate rounding ○ economic disparities that impede telehealth and improve patient experience for telehealth.
<p>There will not be a “new normal” but rather a New Existence for healthcare and human experience Wolf 2020 (27)</p>	<ul style="list-style-type: none"> • Practical efforts for a new existence are clear and already in process in various forms. In particular for healthcare, we will be called to: <ul style="list-style-type: none"> ○ rebuild consumer confidence and address the fears and needs of patients and families ○ recharge our workforce to address issues of stress, trauma and burnout ○ rebalance models of care where virtual care is more widely accepted and expected ○ reinstate responsible access and visitation policies that balance clinical and personal needs ○ refresh our capacity as we prepare for any resurgence of cases.

Source	Advice
<p>The essence of human experience in the face of COVID-19</p> <p>Wolf 2020 (28)</p>	<ul style="list-style-type: none"> • Even in the face of limited visitation policies, organisations are finding technology and other means to connect people to one another, to enable those in isolation to feel less alone and provide a face and voice of comfort, even if not in person, at the end of life. • We are seeing the human spirit personified in the efforts of so many on the front lines of care hidden behind masks and screens putting a picture of themselves with a smile and even a note or two about who they are as a person on the front of their gown. • Caring for healthcare teams has been elevated to new heights from social-emotional needs of having support lines and respite rooms to ensuring basic needs are met in providing internally- developed markets to provide for food and sundry needs for those focused on healing others.
<p>Virtual care visits: delivering care that is patient-centered and compassionate</p> <p>Dionne 2020 (29)</p>	<ul style="list-style-type: none"> • Advice for providers asking ‘How do I continue to honour the provider-patient relationship during virtual care visits?’. The answer is threefold: 1) trust the technology; 2) trust yourself; and 3) trust your patients. <ul style="list-style-type: none"> ○ Attend and review training sessions offered until confident; rally with fellow colleagues to share best practices. ○ Share your screen to invite patients to see important images. ○ Use the TeachBack tool to ensure patient understanding. ○ Invite patients to share what they appreciated about the virtual visit and how you can improve their experience.
<p>Involving consumers in your health service or facility’s COVID-19 response</p> <p>Health Consumers NSW 2020 (30)</p>	<ul style="list-style-type: none"> • It’s essential to involve consumers in key strategic and operational COVID-19 decisions and communication. If you involve clinicians in the planning and decision-making, then also involve consumers with lived experience of your health services. • Use established networks to find consumers quickly and easily. • Consumers will help ensure that you are making the right decisions as they will understand the potential community impacts. Consumers will also help with messaging of those decisions.

Source	Advice
<p>How will COVID-19 change patient experience, healthcare delivery? Heath 2020 (31)</p>	<ul style="list-style-type: none"> Organisations must also assess how they are assuring they have the appropriate resources – both human and material – and emotional support for nurses. This will allow nurses to continue efforts for patient-centred care.
<p>How coronavirus is affecting the patient experience with Dr. Adrienne Boissy Boissy 2020 (32)</p>	<ul style="list-style-type: none"> Consider messaging and ensure communication is empathic to the experience and the fear that patients and caregivers are experiencing in response to COVID-19. Ensure patients have access to spiritual care 24/7 if they have tested positive for COVID-19.
<p>Tools to support communication between patients and families NSW Health Critical Intelligence Unit 2020 (33)</p>	<ul style="list-style-type: none"> A rapid evidence review on virtual visiting solutions, smart devices (for video conferencing apps such as Skype, WhatsApp, Facetime to support communication between patients and their families during the COVID-19 pandemic.
<p>COVID, kidneys & coping: ask your social worker Mason 2020 (34)</p>	<ul style="list-style-type: none"> Tips and tools for coping with a pandemic including self-care, getting back to a new normal including returning to work or sending children back to school, managing practical concerns, worries and anxieties.

Source	Advice
<p>Making informed housing decisions during a pandemic</p> <p>McMaster University 2020 (35)</p>	<ul style="list-style-type: none"> • During the COVID-19 pandemic, should I or my family member go to live with family or stay in the long-term care or nursing home or in my retirement or assisted living home? <ul style="list-style-type: none"> ○ COVID-19 poses significant health risks for seniors and those with compromised immune systems. For those living in long term care homes and nursing homes, the decision to move back home with friends and family can be difficult to make. It's important to ensure that you will have proper care if you decide to move out. Use this decision aid to help you consider your options.
<p>Coronavirus disease 2019 (COVID-19) shared decision-making tool</p> <p>National Hospice and Palliative Care Organisation 2020 (36)</p>	<ul style="list-style-type: none"> • The tool provides an opportunity for proactive informed decision-making to ensure seriously ill individuals can make their wishes known and access care concordant with their preferences as available.

Source	Advice
<p>What Australia's Health Panel said about Telehealth - March/April 2020</p> <p>Consumer Health Forum, 2020</p>	<ul style="list-style-type: none"> • During March 2020, Australia's Health Panel (AHP) asked panellists about their views and perceptions on the use of telehealth in Australia. • Overall, 95 panellists participated in this survey, with most of them being female (74%, n=68) and aged 46 or older (90%, n=82). Interestingly 44% (n=40) were aged 65 or older, putting them in a demographic more likely to have engaged in telehealth before the COVID-19 pandemic. • The vast majority (98%, n=91) had heard of telehealth but only one third (34%, n=32) had ever been offered a telehealth service as an option for their healthcare. However, of those who have been offered a telehealth service, a significant majority of 88% (n=26) had ended up using that service. • The two most common types of healthcare service consumers were offered via telehealth were for general practice (59%, n=17) and medical specialists (28%, n=8). • The majority of panellists that used telehealth services found it to be of excellent or good quality (82%, n=23), with only one person reporting it be 'poor' and none reporting it as 'very poor'. When compared to regular face-to-face consultations however the panellists were more split: 39% (n=11) believed it was better than face-to-face, 32% (n=9) thought it was worse and 29% (n=8) thought it was more or less the same. Common problems for telehealth included health professionals not embracing the option effectively, technological problems with phone or internet lines, and concern about missing services that could only be done face-to-face, for example, physical examination. • The three largest perceived barriers were 'access to required technology' (58%, n=48), 'unreliable internet access' (54%, n=45) and 'awareness of the option' (52%, n=43).

Table 2: Lessons from previous pandemics to preserve patient experience and person-centred care during COVID-19

Source	Advice
Peer reviewed sources	
<p>People-centred health systems: building more resilient health systems in the wake of the Ebola crisis</p> <p>Martineau 2016 (37)</p>	<ul style="list-style-type: none"> • Many post-Ebola health system strengthening programs are framed around a notion of health system resilience that focuses on global rather than local priorities and fails to account for key local social dynamics that shape crisis responses. Post-crisis health system strengthening efforts require a shift towards a more people-centred understanding of resilience that attends to the people, relationships and local contexts that constitute health systems and the practices that produce crisis responses. • Post-Ebola health system programming requires a shift in policy thinking towards a more local, relational and practice-oriented understanding of health system resilience. Such a shift should start by adapting and applying key insights gained from the recent conceptual shift in health systems and policy research towards people-centred health systems, in particular putting people's voices and needs first, and recognising the central importance of relationships and values in driving system change.
<p>Patient-centred coordinated care in times of emerging diseases and epidemics. contribution of the IMIA Working Group on Patient Safety</p> <p>Borycki, et al. 2015 (38)</p>	<ul style="list-style-type: none"> • New and emerging diseases present opportunities for repurposing existing technologies and for stimulating the development of new innovation technologies, such as new software used for tracking patients during emerging disease outbreaks. The paper describes the development of new technologies and the repurposing and extension of existing ones (such as electronic health records) using the Ebola outbreak.
<p>Modernising epidemic science: enabling patient-centred research during epidemics</p> <p>Rojek, et al. 2016 (39)</p>	<ul style="list-style-type: none"> • The deficiencies of the clinical research response to severe acute respiratory syndrome, pandemic influenza, Middle East respiratory syndrome coronavirus and Ebola virus demonstrate that current research models do not adequately inform and improve the quality of clinical care or public health response. Three suggestions for improvements are made. First, integrate the data and sample collection needs for clinical and public health decision-making within a unified framework, combined with a risk-based, rather than a discipline-based, approach to ethical review and consent. Second, develop clinical study methods and tools that are specifically designed to meet the epidemiological and contextual challenges of emerging and epidemic infectious diseases. Third, invest in investigator-led clinical research networks that are primed and incentivised to respond to outbreak infections, and which can call on the support and resources of a central centre of excellence.

Table 3: Patient experience and person-centred care in renal care

Source	Advice
Peer reviewed sources	
<p>Person-centered integrated care for chronic kidney disease: a systematic review and meta-analysis of randomized controlled trials Valentijn, et al. 2018 (40)</p>	<ul style="list-style-type: none"> • Person-centered integrated care has been advocated as a way to improve the management and health outcomes of people with chronic kidney disease. • Person-centered integrated care may have little effect on mortality or quality of life. The effects on serum creatinine, estimated glomerular filtration rate, and renal replacement therapy are uncertain, although person-centered integrated care may lead to fewer hospitalisations and improved blood pressure control.
<p>Costs and outcomes of advance care planning and end-of-life care for older adults with end-stage kidney disease: a person-centred decision analysis Stellars 2019 (41) (3)</p>	<ul style="list-style-type: none"> • Economic evaluations of advance care planning (ACP) in people with chronic kidney disease are scarce. Hospital costs and outcomes of a nurse-led ACP intervention compared with usual care in the last 12 months of life for older people with end-stage kidney disease managed with haemodialysis was examined. • The mean cost of ACP was AUD\$519 per patient. The mean hospital costs of care in last 12 months of life were \$100,579 for those who received ACP versus \$87,282 for those who did not. The proportion of patients in the model who received end-of-life care according to their preferences was higher in the ACP group compared with usual care (68% vs. 24%). The incremental cost per additional case of end-of-life preferences being met was \$28,421. The greatest influence on the cost-effectiveness of ACP was the probability of dying in hospital following dialysis withdrawal, and costs of acute care.
<p>Patient and caregiver values, beliefs and experiences when considering home dialysis as a</p>	<ul style="list-style-type: none"> • 43 patients [pre-dialysis (n=18), peritoneal dialysis (n=13), home haemodialysis (n=4) and facility haemodialysis (n=9)] and 9 caregivers participated in interviews.

Source	Advice
Peer reviewed sources	
<p>treatment option: a semi-structured interview study Walker, et al. 2016 (42)</p>	<ul style="list-style-type: none"> Five themes identified related to home dialysis: lacking decisional power (complexity of information, limited exposure to home dialysis, feeling disempowered, deprived of choice, pressure to choose), sustaining relationships (maintaining cultural involvement, family influence, trusting clinicians, minimizing social isolation), reducing lifestyle disruption (sustaining employment, avoiding relocation, considering additional expenses, seeking flexible schedules, creating free time), gaining confidence in choice (guarantee of safety, depending on professional certainty, reassurance from peers, overcoming fears) and maximising survival.
<p>Patient-centered care in renal medicine: five strategies to meet the challenge O'Hare 2018 (43)</p>	<ul style="list-style-type: none"> There is growing interest in patient-centered care, defined as 'care that is respectful of and responsive to individual patient preferences, needs, and values'. Although generally accepted as uncontroversial, the notion of 'centering' care on patients is in fact quite revolutionary. Because medical teaching, research, and practice have traditionally been organised around diseases and organ systems rather than patients, making care more patient centered would require no less than a paradigm shift. Simple practices include: a willingness to listen, make time, go beyond our job description, re-imagine what it means to provide good care, and see value in relationship building.
<p>Patient-reported outcome measures for adults with kidney disease: current measures, ongoing initiatives, and future opportunities for incorporation into patient-centered kidney care Nair 2019 (44)</p>	<ul style="list-style-type: none"> This narrative review provides a comprehensive list of existing patient reported outcomes measures developed for adults with kidney disease with information on their gaps and limitations; a rationale to support the continued incorporation of patient reported outcomes measures into nephrology clinical trials, clinical care, and health care policy; and a summary of ongoing initiatives and future opportunities.
<p>From patient-centered to person-centered care for kidney diseases Morton, et al. 2019 (3)</p>	<ul style="list-style-type: none"> Person-centred care represents a shift from the historical way nephrology services were designed to operate because it places an equal footing an individual's preferences, needs, and values as they evolve over time, as well as taking into account any other personal circumstances.

Source	Advice
Peer reviewed sources	
	<ul style="list-style-type: none"> • The potential implications of a move to person-centred care from disease-centred or patient-centred care include a collaborative approach to care, using shared goals rather than prescribed targets; a greater understanding by the individual of their condition and their treatment, which leads to better decision-making and a more positive experience of care; and, with increased input from the people who use kidney services and the people responsible for them, a better co-design and coproduction of kidney services.
<p>Exploring views on what is important for patient-centred care in end-stage renal disease using Q methodology</p> <p>Cramm, et al. 2015 (45)</p>	<ul style="list-style-type: none"> • Four views on person-centred care among patients in a haemodialysis department and the professionals treating them suggest that there is no one size fits all strategy for providing person centred care to patients with end-stage renal disease. Considerations include: <ul style="list-style-type: none"> ○ listening to patients and taking account of their preferences in treatment decisions is considered central ○ providing comprehensible information and education to patients so that they can take charge of their own care ○ aspects related to the atmosphere at the department ○ professional or acquaintance that acts as care coordinator, making treatment decisions with or for them.
<p>Achieving a person-centered approach to dialysis discontinuation: an historical perspective</p> <p>O’Hare, et al. 2019 (46)</p>	<ul style="list-style-type: none"> • Dialysis discontinuation remains a conundrum for patients, families, and professionals. While contemporary clinical practice guidelines support a person-centred approach toward stopping dialysis treatments, this often occurs in a crisis when all treatment options have been exhausted.

Source	Advice
Peer reviewed sources	
	<ul style="list-style-type: none"> • Relatively little is known about the impact of dialysis discontinuation on the experiences of patients and families and there is a paucity of high-quality person-centred evidence to guide practice in this area. • Clinicians need better insights into decision-making, symptom burden, and other palliative outcomes that patients might expect when they discontinue dialysis treatments to better support decision-making in this area.
<p>Hard choices, better outcomes: a review of shared decision-making and patient decision aids around dialysis initiation and conservative kidney management</p> <p>Davis, et al. 2017 (47)</p>	<ul style="list-style-type: none"> • Patients reaching end-stage kidney disease face difficult decisions, including choosing among renal replacement therapies. With an increasingly elderly and frail population, there is growing interest in conservative kidney management as a viable alternative to dialysis. Shared decision-making is a patient-centred approach to these decisions, in which choices are viewed within the explicitly discussed values and preferences of the patient. Patient decision aids are tools designed to facilitate these discussions. The choice between dialysis and conservative kidney management is particularly complex, given the poor prognostication data. This is an emerging area for patient decision aids in nephrology
<p>A patient-centred approach to measuring quality in kidney care: patient-reported outcome measures and patient-reported experience measures</p> <p>Aiyegbusi, et al. 2017 (48)</p>	<ul style="list-style-type: none"> • Patient reported outcome and experience measures may facilitate the measurement of quality in renal care and aid the tailoring of care to individual patients. Patient reported outcomes measures may have a potential role as prognostic markers.
<p>Person-centered care for older adults with kidney disease: core curriculum 2019</p>	<ul style="list-style-type: none"> • This article models a person-centered approach to care for older adults with kidney disease. Background information is provided on the principles of person-centered care and outline ways in

Source	Advice
Peer reviewed sources	
Freidin, et al. 2020 (49)	which this approach contrasts with the more disease-based approaches that dominate current medical education and practice.
Patient-to-patient peer mentor support in dialysis: improving the patient experience Bennett, et al. 2018 (50) (4)	<ul style="list-style-type: none"> • Greater focus on patient-reported outcome measures for dialysis patients and an increased patient engagement focus has highlighted a lack of formal patient-generated strategies. • Research studies describe the benefits of peer mentor programs in dialysis to include: improved goal setting, decision-making and increased self-management. While a variety of program formats exist, a combination of face-to-face and telephone peer support models are recommended and formal training of mentors is required.
Barriers to education and shared decision making in the chronic kidney disease population: a narrative review Cassidy et al. 2020 (51)	<ul style="list-style-type: none"> • Provision of education to inform decision making for renal replacement therapy is a key component in the management of chronic kidney disease, yet patients report suboptimal satisfaction with the process of selecting a dialysis modality. • Standardised comprehensive renal replacement therapy education programs through multidisciplinary health teams can help optimise chronic kidney disease, patient education and shared decision making. Involving patients in the research process itself and implementing patient values and preferences into clinical guidelines can help to achieve a patient-centered model of care.
An exploratory study of person-centered care in a large urban hemodialysis program in Canada using a qualitative case-study methodology Lewis et al. 2019 (52)	<ul style="list-style-type: none"> • A single hemodialysis program found limited evidence of person-centred care. Overall, patients reported that their care was good and they had positive relationships with their care team. However, they did not feel involved in decisions regarding their care or consider it to be individualised. • In general, providers acknowledged the potential benefits of person-centred care, but were constrained in their practice by a number of factors, including individual perceptions of their role, a prescriptive care environment, and an organisational focus on managing demand.

Rapid evidence checks are based on a simplified review method and may not be entirely exhaustive, but aim to provide a balanced assessment of what is already known about a specific problem or issue. This brief has not been peer-reviewed and should not be a substitute for individual clinical judgement, nor is it an endorsed position of NSW Health.

Appendix

PubMed search terms

((2019-nCoV[title/abstract] or nCoV*[title/abstract] or covid-19[title/abstract] or covid19[title/abstract] OR "covid 19"[title/abstract] OR "coronavirus"[MeSH Terms] OR "coronavirus"[title/abstract] OR sars-cov-2[title/abstract] OR "severe acute respiratory syndrome coronavirus 2"[Supplementary Concept])) AND (("Family-Centered"[title/abstract] OR "patient-centered care"[MeSH Terms] OR "patient experience*" [title/abstract] OR "patient centered"[title/abstract] OR "person centered"[title/abstract] OR "patient centred"[title/abstract] OR "person centred"[title/abstract] OR "patient-oriented"[title/abstract] OR "patient-oriented"[title/abstract] OR "Patient-focused"[title/abstract] OR "person-focused"[title/abstract] OR "consumer participation"[title/abstract] OR "shared decision*" [title/abstract] OR "client-focused"[title/abstract] OR "client-oriented"[title/abstract] OR "client-centered"[title/abstract]))

((2019-nCoV[title/abstract] or nCoV*[title/abstract] or covid-19[title/abstract] or covid19[title/abstract] OR "covid 19"[title/abstract] OR "coronavirus"[MeSH Terms] OR "coronavirus"[title/abstract] OR sars-cov-2[title/abstract] OR "severe acute respiratory syndrome coronavirus 2"[Supplementary Concept])) AND (("Family-Centered"[title/abstract] OR "patient-centered care"[MeSH Terms] OR "patient experience*" [title/abstract] OR "patient centered"[title/abstract] OR "person centered"[title/abstract] OR "patient centred"[title/abstract] OR "person centred"[title/abstract] OR "patient-oriented"[title/abstract] OR "patient-oriented"[title/abstract] OR "Patient-focused"[title/abstract] OR "person-focused"[title/abstract] OR "consumer participation"[title/abstract] OR "shared decision*" [title/abstract] OR "client-focused"[title/abstract] OR "client-oriented"[title/abstract] OR "client-centered"[title/abstract]))

"Kidney Failure, Chronic"[Majr] AND (("Family-Centered"[title/abstract] OR "patient-centered care"[MeSH Terms] OR "patient experience*" [title/abstract] OR "patient centered"[title/abstract] OR "person centered"[title/abstract] OR "patient centred"[title/abstract] OR "person centred"[title/abstract] OR "patient-oriented"[title/abstract] OR "patient-oriented"[title/abstract] OR "Patient-focused"[title/abstract] OR "person-focused"[title/abstract] OR "consumer participation"[title/abstract] OR "shared decision*" [title/abstract] OR "client-focused"[title/abstract] OR "client-oriented"[title/abstract] OR "client-centered"[title/abstract]))

Google and Twitter search terms

Search terms: "person centred/centered care" AND "patient experience" and "COVID-19" #ptexp

Search terms: "person centred/centered care" OR "patient experience" AND "renal" OR "dialysis unit" OR "kidney failure"

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