HEALTH CONSUMERS NSW

COVID-19
Consumer Leaders
Taskforce

AUGUST 2020

Visiting Guide

ENABLING FAMILY PRESENCE IN A COVID-19-NORMAL WORLD

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ACKNOWLEDGEMENTS

Visiting Guide: Family Presence in a COVID-19 normal world

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Disclaimer

The views expressed in this Guide are those of the authors and contributors and not necessarily of organisations they may also be affiliated with. The Guide is intended to help inform the development of effective family presence and visiting policy and practice during COVID-19 across NSW.

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"I just wanted to pass on my genuine thanks in making my parent and our entire family feel welcome. During this time, we have all had to deal with the COVID-19 crisis and the staff and management have gone above and beyond to ensure that we can still visit our loved ones during this time.

They are always welcoming and ensured that all checks are completed prior to entering the facility. I thank [our nurse] who identified an issue and provided a solution to ensure my parent was happy and comfortable. It really made us feel that everyone matters to the staff and I personally couldn't be happier with the care and attention my parent receives."

SUMMARY AND PRINCIPLES

As NSW grapples with a global pandemic, there is widespread gratitude for the hard work and dedication of NSW Health staff, clinicians and management for the effective NSW Health response. While successful, the response has also had a range of negative, unintended and significant consequences to patients and families navigating a very different health care landscape. This Guide focuses specifically on the separation of patients from their families and care partners, and identifies principles that can be incorporated into visiting policy and practice for a COVID-19-normal world.

Purpose

Family presence arose as a priority area by the COVID-19 Consumer Leaders Taskforce NSW, and the resultant Principles developed by the Taskforce with input from the Consumer Representative Hub and facilitated by Health Consumers NSW.

This Guide was developed in response to the challenges faced by NSW Health with protecting staff, patients, families, and all who enter the facilities, from COVID-19. Its intent is to inform and bring to the fore patient and family perspectives around the issues faced by restricting patients' visitors into health facilities, and creates principles to guide decisions and their implementation.

It recognises each of the stakeholder groups as essential and significant players in keeping each other safe and acknowledges that no one stakeholder group can succeed alone. It accepts that all stakeholders are dependent on each other.

The Guide is pragmatic and takes a risk mitigation approach. It acknowledges the immense threat of COVID-19 to patients, staff and others. However, it also recognises the evidence-based risks associated with removing or restricting family presence on patient outcomes. The Guide advocates risk mitigation is applied to both sets of risks i.e. taking a systematic approach to family presence, considering the whole patient journey, and including all relevant expertise.

Who are we?

The COVID-19 Consumer Leaders Taskforce comprises of leading Consumer Representatives in NSW and was formed in April 2020 to support the COVID-19 response. The activity and outputs of the Taskforce has been facilitated by Health Consumers NSW, and supported by a broader base of consumer representatives through the HCNSW Consumer Representative Hub.

Who are we talking to?

The Guide has been written to be considered and incorporated into system-wide family presence and visiting planning. It should be applied at a health system level, service level, and at the bedside with individual interactions. The intended audience is people creating, reviewing, and implementing visiting policies; front line staff who implement such policies and make decisions about patients receiving visitors; and health consumer representatives involved in shaping and advocating patient centred care in health services. As a result, it will be distributed broadly to health services in NSW, including NSW Health (Local Health Districts, Health Networks, Pillar organisations) and to NGO and for-profit health care providers.

What specifically are we talking about?

This Guide applies specifically to hospitals and other health care facilities, where patients are receiving care either as inpatients or outpatients. Although not specifically targeting aged care facilities, the principles of family presence apply equally validly, and at least as importantly.

The Guide also differentiates 'Visitors' into two groups: family and friends who patients choose to have by their side at critical points in their treatment or care; and others, who the Guide describes as 'well-wishers'.

The problem

COVID-19 has resulted in infection control being steadfastly prioritised over all other risks. However, there is substantial evidence that family presence significantly improves patient outcomes over a wide range of measures, as well as reducing adverse events.

The balance is:

- The risk that family presence may pose; and
- Risk that family presence restrictions may create in the short and long term.

Critical Issues

Critical issues that have impacted patients and families as a result of COVID-19 are:

- Patient and family isolation and disconnection, especially at critical times in their treatment and care;
- Patient and family distress at not being able to receive spiritual care or direction, as a result of chaplains and clergy not being able to attend patients;
- Staff fear and anxiety of visitors contributing to unsafe workplaces – compounding already heightened fear of COVID-19 risk in their work;
- Minimise the spread of COVID-19;
- Confusion and inconsistency created from the uncertainty of an unfamiliar and changing environment.

Goals

This Guide seeks to support effective family presence policies and practices, through:

1. Recognising and accepting family presence as the accepted norm, while minimising the risk of infection introduction and spread;
2. Explore new and innovative ideas and solutions with patients and families, as partners;
3. Plan as a system; apply locally; and review on facts as the situation changes
4. Restore and revitalise stakeholder confidence – 'Together, we've got this!'

Principles

In order to achieve these goals, nine principles have been identified that can be applied to visiting policy and practice for a COVID-19-normal world:

1. **Stakeholder partnership - Nothing about us without us**

   Building on the "Partnering with Consumers" approach well established pre-pandemic.

2. **Focus on the agreed goals and let expertise guide**

   Patient and family expertise for patient needs, infection control expertise for infection control.

3. **Prepare for infection control for all**

   Establish standards for infection control across the board so that the baseline health care environment is set at a COVID-ready level.

4. **Focus on needs and be problem-solvers throughout**

   Allow patient and family needs, balanced with infection control needs, to guide ideas and responses for desired outcomes.

5. **Identify risks of negative consequences and explore options to mitigate**

   Recognise and prepare for the negative impacts of decisions made in order to minimise them.

6. **Fill the need gap where physical family presence is not possible**

   Non-physical, real time alternatives should be in place and made available to support patients and families.

7. **Plan ahead; Prepare as a system; Apply locally**

   Consistent approach developed in partnership at the system level, applied in partnership at local level. Build flexibility and pathways for the foreseen and unforeseen.

8. **Communicate factually, consistently, clearly and widely**

   Using relevant expertise, using clear accessible language and channels, communicating widely and early.

9. **Continually re-assess the environment for changes; and refine iteratively**

   Make decisions based on the current situation and adapt as circumstances change and as we learn more.

Call to action

Together NSW has achieved exceptional results in the face of this one in a hundred year pandemic. Unfortunately, these results have been achieved at great cost, including separating patients and families from each other at difficult and critical times.

Now as we move out of the initial crisis response it is crucial to reflect and adapt on how we can together find an equally rigorous, but more compassionate and creative approach to safely supporting family presence. We need to establish our new COVID-19 normal. We are confident this can be achieved through working together in partnership, building on and extending the "Partnering with Consumers" approach well established pre-pandemic.

The COVID-19 Leaders Taskforce NSW strongly recommends that the Principles in this Guide be incorporated into reviewing and refining family presence responses to prepare for the significant uncertainty COVID-19 presents.

CONTENTS

BACKGROUND

Coronavirus has impacted almost every aspect of health care service.

The looming crisis, generated as a result of the escalating global pandemic, focused minds on infection control. This Guide fully supports infection control as fundamental for safe, high-quality care.

Witnessing the extent of the catastrophic impact faced by other countries in real time, has also given Australian leaders a glimpse of the issues as they arise, and the challenges faced. We are privileged to observe and learn from the successes and lessons of others.

To date, Australia, and particularly NSW, has fared particularly well largely as a result of quick, decisive actions based on the advice of experts and the experience of history. However, recent infection flare ups remind us that the pandemic is far from over.

The opportunity now is to take all this expertise and review initial reactions. Then, moving forward, to prepare responses that are socially sensitive and able to adapt to this fluid and uncertain environment. This document aims to create a set of expectations and outcomes key stakeholders can agree to and incorporate into planning and practice.

METHOD

Family presence arose as a priority area by the COVID-19 Consumer Leaders Taskforce NSW, and the resultant Guide developed by the Taskforce with input from the Consumer Representative Hub. The Taskforce, Consumer Representative Hub and development of this guide have all been facilitated by Health Consumers NSW.

This work brings together personal experiences, observations and feedback gathered since February 2020 and the onset of COVID-19; expertise of leading consumer representatives who are attuned to and experienced with system and service responses; and lessons learned by health peers both locally and internationally.

Contributions and observations were gathered from a range of sources including Amplify, the online engagement platform of Health Consumers NSW, a public event for consumers held 29 June 2020 "Tell us about ... visiting hours". Additional feedback sources also included personal experiences from consumer representatives or as shared with consumer representatives and

advocates; Care Opinion search results (careopinion.org.au); media and social media sources. (For more information visit APPENDIX B: How we arrived at this report.)

Most of the feedback has been gathered from NSW experiences, although the inclusion of feedback was not limited to NSW where the feedback reflected issues also relevant to NSW. A very small number of experiences are from aged care facilities – also only included where the feedback reflects issues relevant to health facilities, COVID-19, patients, and family presence.

COMMON GROUND

This Guide recognises COVID-19 as our common threat. It also recognises each of the stakeholders noted below as essential and significant players in keeping each other safe. None can succeed alone. And all need to rely on each other:

- Health staff and other workers must have confidence that they can come to work and then go home without unduly risking either themselves, their families or their patients;
- Patients (and their families) must have confidence that they can seek care, and will receive it uncompromised and in ways that will facilitate their healing;
- Community must have confidence that the provision of these health services is not leaking infection more broadly;
- Policy makers must get adherence from all.

All share the same common ground – to be safe and be confident that they can provide or receive uncompromised health services without unduly risking themselves and each other.

PROBLEM

"We are seeing COVID-centred care, not patient-centred care."

The challenge being grappled with is that to fully minimise the risk to staff and community would empty our hospitals of patients. Outside of COVID-19, low patient presentations has already occurred - in hospitals, in emergency departments, in GP and specialty clinics, and in ancillary care.

Illness, accidents and life events such as childbirth and death, continue despite pandemic concerns. Appropriately, our infection control has been steadfastly prioritised. However, this has given rise to adverse impacts on undetected, untreated, or unmanaged illness or injury, as well as sidelining life events and social norms.

Managing infection control in isolation is not enough.

The balance we must address is[1]:

- The risk that family presence may pose; and
- Risk that family presence restrictions may create in the short and long term.

"I was transferred from the Emergency Department late at night.

I became teary and distressed. I tried to be quiet to not disturb the sleeping patients in the room. I felt uncomfortable. I did not feel supported. It was difficult being alone after midnight with no family or friend to advocate for me."

[1] Planetree, Guidelines for Preserving Family Presence in Challenging Times, released 28 May 2020

How does this affect patient visiting policy?

There are 2.86 million Australians providing informal, unpaid care. On average, each of these Australians spend 13 hours of their week caring, amassing a staggering 1.9 billion hours each year.[2,3] Loosely, they are the family and friends of the individuals they support. These informal carers contribute to the wellness and welfare of people who may be regular or occasional patients within our health facilities. Whilst they may be considered incidental visitors into a health care facility, in practice they are care partners.

Whilst noting that the language of 'visitors' largely understates the contribution to their patients. These people are the group of 'visitors' this Guide focuses on.

"Recently a very young, first-time mother presented in a major public hospital around midnight, gave birth at 7am and was home by 10:30am. Only her husband was allowed to present at the delivery even though she had planned to have her mother present to support them both. Her midwife restricted visits mostly to brief telephone follow-up. After care for mother and baby was minimal and the experience had little of the joy the young family had anticipated. The brief hospital stay was not at the young couple's request. How widespread is this practice?"

Involving family and friends in care improves outcomes by:

- improving communication between clinicians and patients;
- improving patient adherence to treatment and on-going condition management[4];
- minimising preventable risks and reducing adverse events[5],[6];

[2] Deloitte Access Economics, **The Economic Value of Informal care in Australia in 2015**, Carers Australia, June 2015

[3] Australian Institute of Health and Welfare, **Australia's Welfare 2015**

[4] Vermeire E et al, Patient Adherence to Treatment: Three Decades of Research. A Comprehensive Review, Journal of Clinical Pharmacy and Therapeutics (2001) 26, 331±342

[5] Khan A, et al, Families as partners in Hospital Error and Adverse Event Surveillance, JAMA Pediatrics, 2017;171(4):372-381

- supporting smoother transitions for patients between health care settings and to home;
- improving clinical and personal outcomes;[7,8,]
- influencing patients' willingness to seek and receive care.[9]

"With the coronavirus prompting hospitals to enforce strict visitor policies, many women are leaving the hospital system and looking to birth at home with or without a private midwife."

In turn, involving family and friends gives them the confidence to step back when necessary, and importantly during this time of intense uncertainty, can reduce both patient and family trauma in care scenarios.

Outside of clinical needs, the involvement and presence of family is comforting and calming to anxious and fearful patients. The presence of familiar faces and support offers reassurance in otherwise unfamiliar places. Their presence combats isolation and can even bring joy.

When family are not there, staff and how they manage difficult situations, plays a significant re-assuring role. Their ability to provide this often requires creative, unique and sensitive solutions, that are appreciated by both the patient and family. Provision of these solutions can facilitate communication and provide confidence in the care, now and in the future. It builds trust.

[6] Gill F, Leslies GD, Marshall AP, Family Initiated Escalation of Care for the Deteriorating Patient in Hospital: Family Centred-Care or Just "Ticking the Box", Australian J Critical Care 2016;29(4): 195-200.

[7] Bogner, J., et al, Family Involvement in Traumatic Brain Injury Inpatient Rehabilitation: A Propensity Score Analysis of Effects on Outcomes During the First Year After Discharge, 2019, American Congress of Rehabilitation Medicine

[8] Maslakpak MH, Rezaei B, Parizad N, Does Family Involvement in Patient Education Improve Hypertension Management? A Single-Blind Randomized, Parallel Group, Controlled Trial, 2018, Cogent Medicine, 5:1, 1537063

[9] Vermeire E et al, Patient Adherence to Treatment: Three Decades of Research. A Comprehensive Review, Journal of Clinical Pharmacy and Therapeutics (2001) 26, 331±342

"My elderly mum had her birthday yesterday. We couldn't celebrate with her.

The staff organised a Skype call so we could talk to her as she is confined to bed.

For her birthday we bought mum a home speaker so she can listen to music just by speaking to it. The IT staff from the nursing home installed it, put the app on mum's phone and showed her how to use it. They really went out of their way to make it happen in time for her birthday. Even though we can't visit, I know mum is being well looked after. "

TERMINOLOGY: VISITORS, FAMILY, FRIENDS, AND CARE PARTNERS:

In this document, 'family', 'family and friends', 'carers' and 'care partners' are used interchangeably;

- Care partners are the family and friends who patients choose to have by their side at critical points in their treatment or care.
    - As each family is unique, care may be shared and should not be assumed to be a single person. Care arrangements while in hospital and post discharge from hospital or care facility may impact on more than one person in the family;
    - Importantly, 'family' or 'care partners' is not limited to blood relatives;
    - Spirituality and religious practice is important to many people and families. Chaplains, clergy members and/or spiritual leaders (such as Aboriginal or Torres Strait Islander Elders) should be recognised as care partners for some people;

"For a patient to be offered the choice of having their Spiritual person (whether it be Rabbi, Imam, Minister, Guru, Priest or Monk) come to their bedside, or speak on the phone/facetime/skype/zoom. This is an important question to ask a patient and one largely overlooked."

- Individual preference as not all patients want care partners by their side – and that also is their choice.

"It's not always simple. Given the chance I would be involved in conversations and supporting him but he doesn't want looking after. He's only 64 and wants his independence desperately. I do know it makes doctors wary, they wonder what sort of family my Dad has, but they don't know that my Dad didn't explain his illness to us until he was in intensive care and the surgeon sat me down. He doesn't tell us he's in hospital until he's about to be discharged and only answers his phone when he's well. So you can't always judge."

During this time of pandemic considerations and a mobile society, 'well wishers' need also to be considered as part of holistic care for the patient.

"Some people don't have close family, friends or carers, and well-wishers are very important to them."

"

"My parent is dying from cancer and was recently admitted to Hospital. Only 1 designated person is allowed to visit. We chose my other elderly parent. Their English is poor.

I called to see how my parent was going but was told that, due to patient confidentiality, they could only say that they were ok. I was told that once a patient's health degenerates further and requires palliative care, the rules are slightly relaxed. My parent is rapidly deteriorating.

Such unyielding, inhumane protocols, totally disregard the emotional, psychological and spiritual well-being of both patients as well as their loved ones.

The risk of contracting COVID-19 today is, in my opinion, negligible*. I feel the emotional and psychological well-being of all patients and their loved are drastically compromised. I feel betrayed and violated by our medical administrative system. This is all wrong!" *Shared late June 2020, Sydney

CRITICAL ISSUES TO ADDRESS

- Patient and family isolation and disconnection:
  - Compounding fear and anxiety created by illness and injury and overlayed with COVID-19;
  - Safety and care gap when family are absent – having family present contributes to better care;
  - Family involvement in sharing information and decision making;
- Staff fear and anxiety of visitors contributing to unsafe workplaces – compounding already heightened fear of COVID-19 risk in their work;
- Minimise the spread of COVID-19;
- Confusion and inconsistency created from the uncertainty of an unfamiliar and changing environment.

"Some wards have put in very tight restrictions around visitors, while others have been quite relaxed. I think like us, they are struggling to balance infection control with family members attending patients."

"We have seen a change in person-centred care and have many staff unsure of the rules or policy regarding visiting hours. We have staff confused, and therefore reverting to saying 'no'. It is making people afraid to visit and impacts patient support networks."

GOALS: OPTIMISING FAMILY PRESENCE AND VISITING POLICIES AND PRACTICE DURING COVID-19

"Wow, just wow! So much care, so much love. I got myself into a situation where I couldn't help myself but I was lucky to have the most beautiful nurses and support people around me; I felt they listen to you, they hear you, they encourage you. Isolation is one thing I never thought I could handle but these nurses made sure I didn't feel lonely.

My appreciation and love to you all. Thank you, thank you, thank you, for keeping me sane, safe and getting me healthy. It's you guys that make that place a good place to be..."

Visiting and family presence policies and practice must encompass patient, family and infection control needs in order to achieve the best outcome for all parties. This can be achieved with consideration of the following:

1. Balance patient and family needs with infection control needs, to guide ideas and responses for desired outcomes:
    a. Minimising the risk of infection introduction and spread;
    b. Recognising and accepting family presence as the accepted norm:
        i. To connect patients and families to each other as needed;
        ii. To connect families with treating teams at critical points where information is being shared and decisions being made in real time;

2. Recognising the importance of spiritual care and the importance maintaining connection with chaplains, clergy, and spiritual leaders.
3. Explore new and innovative ideas and solutions with patients and families, as partners;
    a. Using technology as ways to facilitate contact;
    b. Allowing patients and families to create the best ways to maintain contact.
4. Plan ahead: prepare as a system; apply locally; and review on facts as the situation changes
    a. Recognise there is a system response, a service response, and an individual response;
    b. Patients and families are involved, at all levels, as equal partners;
5. Restore and revitalise stakeholder confidence – 'Together, we've got this!'
    a. Policies and practices are confidently and compassionately applied true to their original intent
    b. Communicate at all levels – system, service and community.

"Due to unexpected hospital admission for declining health care, a frail, aging and acutely unwell patient was admitted, then transferred for Palliative Care planning and management.

Being hard of hearing, their caring spouse attended with them. Unfortunately, their children live away. COVID-19 made their connection in person prohibitive.

The family welcomed a Haematologist update and opinion to guide their understanding and family plans. Doing so, meant the beginning of a complex connection plan including multi-sites, specialists and technologies.

At very short notice, multiple teams from multiple hospitals, worked with Telehealth to strategise the connection, including connecting one child from Perth and interstate Victoria to connect the other child.

It was a delicate and sensitive conversation being shared across many miles, through innovative technology allowing hearing and vision sharing.

The ability to bring this family together in real-time was most significant,

PRINCIPLES

In order to achieve these goals, nine principles have been identified that can be applied to visiting policy and practice for a COVID-19-normal world:

1. Stakeholder partnership - Nothing about us without us

Building on the "Partnering with Consumers" approach well established pre-pandemic.

Recognition of the stakeholders, at this time of pandemic concerns is key to negotiating the needs of all.

- Visiting policies are about patients and families;
- Patients and families are key stakeholders with diverse needs – rather than a single homogeneous group;
- Each of the key stakeholders are essential and have a role to play in keeping each other safe. None can succeed alone. And all need to rely on each other. Key stakeholders include:
    - Patient, family representatives including community leaders;
    - Front line clinical, social and support staff;
    - Quality, safety and Infection control experts;
    - Executive and policy staff.
- Their working relationship is in partnership, collaboration and reciprocity. To succeed, they will share the commitment, the goals, the decisions, the actions, and the outcomes;
- Patients, families, and their representatives must be involved widely and deeply as partners from designing system goals and settings through to decisions at the bedside;
- Patient feedback and wide consumer and community representation is core to capturing, identifying and addressing diverse needs.

2. Focus on the agreed goals and let expertise guide

Patient and family expertise for patient needs, infection control expertise for infection control.

Patient expertise: guided by health consumers, patients and families

- To differentiate visitors between 'well-wishers' and 'care partners' – and how to respond accordingly;
- Family presence needs – how to identify who patients want by their side and when they need them; and how to handle when:
    - The patient at the bedside is not able to advise, or is at a point of significant vulnerability, how staff can pre-emptively identify family members to attend;
    - A nominated family member/s is stopped at entry screening; how to identify alternative support people nominations;
    - Patients and/or families may want a Chaplain, clergy member or spiritual leader as a care partner;
    - The patient chooses not to nominate anyone as their care partner (as is their choice), along with their right to change their mind at any time.
- How to minimise unnecessary visits; and how patients and families communicate visitation arrangements to their well-wishers;
- And contribute to managing issues that arise and problem solving;

Infection control expertise - guided by clinicians and infection control experts

- Stop the infection at entry - Infection control screening protocols for all;
- Stop the spread within the facility – risk-based Infection control practices, applied across the site and for all; On-site separating, social distancing, hand hygiene, increased cleaning, PPE, etc;

Bring expertise together to:

- Pre-emptively plan for rapid responses to adapt to changing environment;
- Consider a pre-determined stepped approach to infection control to match the level of threat and response set by the Government as the situation changes. In doing so, it allows and prepares for considered and swift escalation and de-escalation responses as the risk situation changes;

3. Prepare infection control for all

Establish standards for infection control across the board so that the baseline health care environment is set at a COVID-19 ready level and communicated clearly.

Business as usual pre-COVID	Active COVID-19 Plan: Levels of COVID Infection			
	Level 1 – Well controlled	Level 2 – Escalating on low levels	Level 3 – Rapid escalation Or at-risk patients and areas	Level 4 – Rampant Or COVID patients and areas
Standard	Tighter than Standard	Tighter than Level 1	Tighter than Level 2	Tightest

Infection Control – Plan ahead and prepare the environment

Consider infection control options required to make the facility safer as infection rates change

Funnel the flow of people traffic:

+ Limit the flow of people;
+ Limited entry and exit points;
+ Screen at entry;
+ limited path access to wards;
+ Log those who enter

Hygiene

+ Location and easy access to hand sanitiser and /or soap and water;
+ Option to wash hands regularly;
+ Entry/exits, within wards and public areas;
+ Visual reminder cues – supporting practice from prominent from entrance and throughout facility and rooms

Cleaning

+ Review materials for additional COVID needs;
+ Intensity and frequency

Social Distancing

4m² Social distancing – supported by

+ Furniture placement;
+ Signage advising how many people can enter space to meet guidelines;
+ Where possible, communication prior to better manage visits

Personal Protective Equipment (PPE)

+ Level of availability;
+ Accessibility; and
+ Training for visitors attending patients – COVID, non-COVID, or other infectious disease

Figure 1: Planning Escalating Infection Control Measures for COVID-19

- Clearly articulate what applies under varying stages/levels of restrictions. Over this, we have the flexibility to overlay the protocols to ensure family / friends / care partner presence;
- Communicate this standard clearly, consistently and accessibly across services, addressing language and disability needs;
- Support the community to understand that meeting these infection control protocols is the first step to more equitable, compassionate visitation. People will want to do this when they understand why they are doing it.

4. Focus on needs and be problem-solvers throughout

Allow patient and family needs, balanced with infection control needs, to guide ideas and responses for desired outcomes.

- Use patient, staff and community feedback and wide consumer representation to capture, identify and address diverse needs;
- Harness existing patient experience mechanisms.

5. Identify risks of negative consequences and explore options to mitigate

Where decisions are agreed upon, recognise there will be unintended negative impacts, including on patients and families. Some will be foreseeable. Apply risk mitigation practices, so they are identified and prepared for.

"[Due to COVID] some accommodation facilities are advising patients and families that they can only have one support person … and are advising consumers that if they leave, they cannot come back. So, for [a country family with] a child requiring 10 months of treatment in a metropolitan hospital leaves to go home for a weekend … they cannot return to the same facility."

"After 5 weeks in the palliative care hospice, the COVID lockdown occurred and the two daughters were advised only one could visit for the duration of her admission. No amount of negotiation provided a solution. The other sister was not even allowed to stand in the courtyard out of her Mum's room to wave. The difficult decision was made to transfer her to a private hospital so that the sisters could both continue to visit her. She died 18 days later. We need to come up with better ways to manage the safety for staff and patients while managing the expectations of families and keeping them safe too."

Bring expertise together to:

- Encourage and collect broad patient and staff feedback to identify issues that arise; as well as practice and ideas that might resolve them;
- Be problem solvers - so likely issues are identified, pre-empted and supported with workable alternatives when necessary;

"Now that surgeries and appointments are re-scheduled, some of the local accommodation facilities is not taking bookings. This is making it very difficult for rural and regional health consumers."

- Recognise how stakeholders can do things differently, including what patients and families can do as well, and accommodate where possible;

  For example, some family members may choose to self-isolate in order to maintain physical presence with their at-risk patient. If it reduces infection risk how can staff accommodate this?

"We have restricted visiting hours at hospitals during this difficult time. Most of us are trying to keep within the rules. My spouse was admitted to hospital before all this started and the only places I have been is to visit them and home."

- Minimise the operational burden to front-line staff – systemise options to address and manage the big issues so frontline don't have to.

  For instance, where remote presence is suggested to replace physical presence, support the option by addressing the most common issues it will face – privacy and security, internet connection, access to technology, etc; to avoid having to consider the same issues over and over, and to minimise suggesting options that are too difficult to implement.

6. Fill the need gap where physical family presence is not possible

Non-physical, real time alternatives should be in place and made available to support patients and families.

- Where physical family presence is not possible, the rationale is clearly explained to affected patients and family members;
- Non-physical, **real time alternatives** should be made available to support:[10,11 ,12]
    - Connecting patients and families to each other as they need;
    - Connecting and involving families with treating teams at critical points where information is being shared and decisions being made.
- Alternatives must consider ease of access and use for both staff and patients and families – keep it simple;
- Systemise options to address and manage the big remote access and connection issues by addressing the most common issues it will face – privacy and security, internet connection, access to technology, etc; to avoid having to consider the same issues over and over, and to maximise rapid implementation;
- Existing protocols that may be barriers to alternatives, should be risk-reviewed and, where possible, adapted to support exceptional circumstances and needs.
- Recognise needs of family members when physical family presence is not possible
    - Family members report ongoing distress and trauma at not being physically present, this is heightened when families are not able to visit patients at end of life;
    - Services have a responsibility to ensure that family members have access to appropriate psychological, emotional, and spiritual support when physical presence is not possible.

[10] Mercadante et al., Palliative Care in the Time of COVID-19, 28 April 2020, Palermo Italy, Journal of Pain and Symptom Management

[11] Calton et al., Telemedicine in the Time of Coronavirus, Journal of Pain and Symptom Management July 2020, Vol. 60 No. 1

[12] Hart et al., Family-Centered Care During the COVID-19 Era, Journal of Pain and Symptom Management, 14 April 2020, Baltimore US

7. Plan ahead: Prepare as a system; Apply locally

Consistent approach developed in partnership at the system level, applied in partnership at local level. Build flexibility and pathways for the foreseen and unforeseen.

- Apply principles into local policy and practice;
- Apply consistently and transparently;

> "Recently, my morning visit with my spouse was cut short (due to) not allowing me to accompany my spouse during their session. Then I find out that another patient (had) their visitor present in the gym area with them.
>
> One night, I believe a member of the nursing staff spent the whole hour with a patient sitting holding their hand after I had to leave.
>
> There seems to be one rule for some and another for others."

- Apply compassionately;
- Build in flexibility and pathways for foreseen and unforeseen exceptions – and refine processes to accommodate where warranted;
    - Encourage and capture patient and family feedback for on-going review.

8. Communicate factually, consistently, clearly and widely

Using relevant expertise, using clear accessible language and channels, communicating widely and early.

- Bring expertise together to develop and implement communications, including consumer representatives and community leaders;
- Communicate honestly, consistently, clearly and widely;
- Communicate explaining the rationale and the actions required;
- Communicate in accessible, clear language and communication forms – across ethnicities and communication channels;
- Communicate in advance, where possible, to set the expectations of staff, patients, families and all other guests prior to entering a facility.

9. Continually re-assess the environment for changes; and refine iteratively

Make decisions based on the current situation and adapt as circumstances and as we learn more.

- Base decisions on current facts, available evidence and grounded experience;
- Include patient and clinical feedback;
- Adapt and refine accordingly

CONCLUSION

Together NSW has achieved exceptional results in the face of this one in a hundred year pandemic. Unfortunately, these results have been achieved at great cost, including separating patients and families from each other at difficult and critical times.

Now as we move out of the initial crisis response, and uncertainty continues to prevail, it is crucial to reflect and adapt on how we can together find an equally rigorous, but more compassionate and creative approach to safely supporting family presence. We need to establish our new COVID-19 normal. We are confident this can be achieved through working together in partnership, building on and extending the "Partnering with Consumers" approach well established pre-pandemic.

The COVID-19 Leaders Taskforce NSW strongly recommends that the Principles in this Guide be incorporated into reviewing and refining family presence responses to prepare for the significant uncertainty COVID-19 presents.

"My child recently had an emergency dash to the hospital in the late afternoon. By the time my child was admitted, it was too late for my second child and I to travel back to our rather remote rural property.

The kindness and compassion of accommodating our needs was outstanding, and we are deeply grateful.

The two Nursing Managers assisted us in negotiating the novel challenges surrounding our stay with such grace that they transformed what could have been a very stressful time, into a calm, manageable experience, where I feel everybody's needs were met. They were prepared to spend precious time meeting with us, understanding our predicaments, and addressing them. God bless them!

Compassionate and strong leadership, capable of adhering to complex COVID protocol, while not losing sight of the very real needs of the human beings under their care.

My spouse and I salute them both. The Hospital is in magnificent hands."

APPENDIX A

About Health Consumers NSW

Health Consumers NSW is a membership-based, independent, not-for-profit organisation that promotes and practises consumer engagement in the NSW health sector. We create meaningful partnerships between consumers, the health sector and policy-makers. Our mission: Consumers shaping health in NSW. We promote the best quality, appropriate health outcomes for consumers of health care services. We believe that all perspectives are important and necessary to create better health outcomes for people. Consumer engagement leads to better health outcomes, more efficient and effective services, consumer-centred care and happier patients and staff. We work to ensure that health consumers are involved in the design and delivery of health care in NSW.

Contact Details:

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Website: http://www.hcnsw.org.au/

Online engagement: https://amplify.hcnsw.org.au/

APPENDIX B

How we arrived at this Guide

This Guide was developed following a process that was devised by Health Consumers NSW, and agreed to by the Consumer Leaders Taskforce prior to commencing the review. The Consumer Leaders Taskforce provided guidance, contributed directly to the Guide and supported the broader consultation with the Consumer Rep Hub (https://amplify.hcnsw.org.au/covid-consumer-rep-hub).

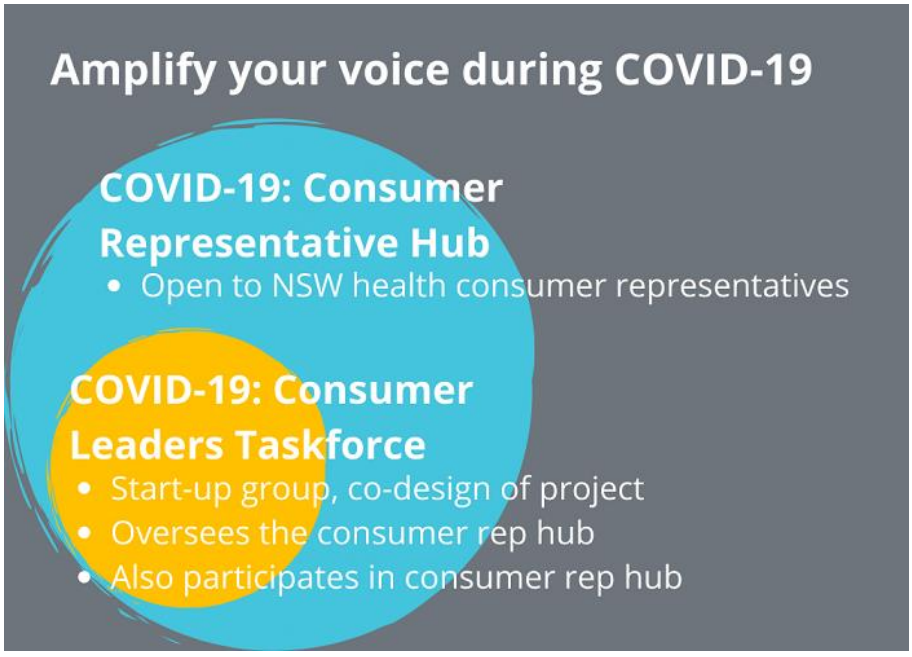

Figure 2: The Consumer Leaders Taskforce and the Consumer Rep Hub

The process was put in place to support rigour and accountability in the Guide's resultant position and recommendations.

This process was conducted remotely using:

- Email
- Zoom meetings/events
- The HCNSW online engagement platform Amplify – amplify.hcnsw.org.au

The process comprised of:

1. The COVID-19 Health Consumers Taskforce held its first exploratory meeting on 22nd April 2020, facilitated and supported by Health Consumers NSW;
2. Taskforce meetings held every 2 to 3 weeks since the initial meeting;
3. Agreement on 3 priority areas to commence with, the first of which was visiting policy, recognised as one of the early casualties of COVID-19;
4. The research phase consisted of two phases:
    a. a quick literature review including reports and recommendations from peer organisations (COVID and non-COVID specific); while simultaneously
    b. gathering feedback as broadly as possible on the impact to patient visiting, specifically (but not exclusively) to NSW and to COVID-19.
5. An event was held on 29th June where the literature was presented, and further feedback and direction sought. The event was open to NSW patients, families, health consumers and consumer representatives.
6. Following the event, feedback continued to be gathered through consumer representative channels, including contributions to The Consumer Representative Hub (on Amplify); as well as feedback from some community organisations;
7. In addition, we also covered a range of media and social media sources; followed discussions and findings from The Beryl Institute; and searched Care Opinion Australia. The feedback was largely unedited, to maintain the integrity of the writers' messages, although most were shortened by omitting minor details focusing on key points. All feedback is unidentified.
8. All feedback was sought, both positive and negative, and collated. We also kept an eye on visiting activity from overseas, particularly the US, Italy and the UK.

9. The writing commenced, and at key points returned back to the Taskforce for their input. The input was discussed, and either incorporated (which most was) or if not, the rationale of the discussion was explained to the member who suggested the edit. The document was better for it.
10. Through this process the final report and its content was developed, refined and finalised.

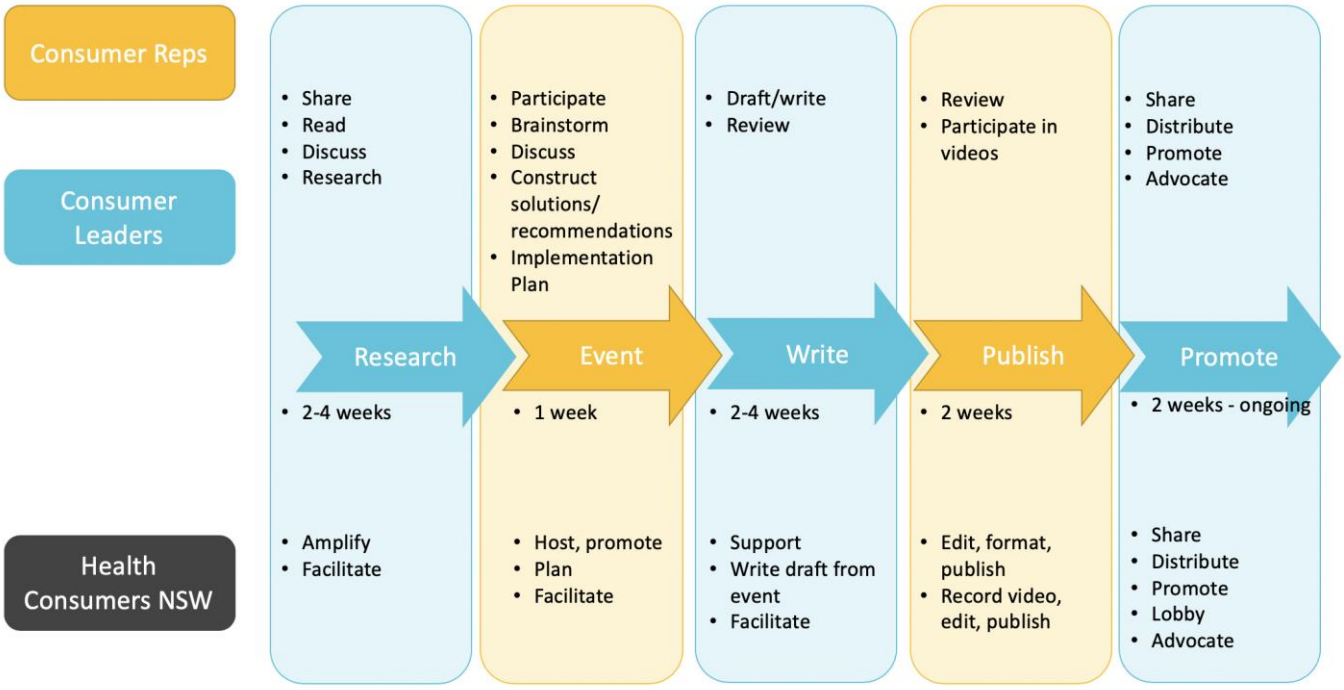

Figure 3: Process map for developing a consumer-led response on priority COVID-19 issues

COVID-19 Consumer Leaders Taskforce

amplify.hcnsw.org.au/covid-consumer-rep-hub

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