



Special Commission of Inquiry into Healthcare Funding

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Health Consumers NSW

Health Consumers NSW (HCNSW) is the peak organisation and advocacy body for health service users in NSW. We are a not-for-profit organisation and a registered charity. We provide a voice for patients, their family members and carers, patient leaders, health consumer representatives in NSW, and health consumer organisations.

Our vision is high-quality health systems, policies, services, and research driven by strong consumer voices [1].

This submission is divided into 3 sections:

- Section 1: Health Consumers – patients, carers, families, and communities
- Section 2: Consumer and Community Engagement – impact of current funding on the effectiveness of current approaches to consumer and community engagement
- Section 3: Systemic Issues – considerations of other system wide issues, identified by consumers and consumer representatives of relevance to the special commission.

This submission reflects the views and perspectives of our members through formal and informal consultations with consumer leaders and consumer organisations. The submission has also been informed by what consumers have told us during other consultation processes, and through staff and volunteers experiences of working closely with NSW Health since 2011. The reports, consultations and needs assessments that have informed this submission are listed in the reference section below.

Health Consumers NSW is happy to provide witnesses to hearings elaborate and clarify any of the issues raised in this submission.

Health Consumers

In this submission, health consumers are defined as people who use, have used, or are potential users, of health services including families and carers. Consumers may participate as individuals or collectively, through informal groups or via consumer organisations [2].

We are aware that the term ‘health consumer’ is contested. Some groups feel the term blurs the distinction between the needs and experiences of patients and carers, while others are critical of the association of the word ‘consumer’ with market-based approaches to delivering healthcare. The term was originally used by consumers of mental health services in the 1990s as part of a rights-based discourse. It is in this spirit that we use the term.

Health Consumer Representative

A health consumer representative is a health consumer who has taken up a specific role to provide advice on behalf of consumers, with the aim of improving healthcare. A consumer representative is often a consumer member of a committee, project, or event, who voices consumer perspectives and take part in decision making on behalf of consumers [2]. Health consumer representatives contribute to design and delivery of health services, health policy, and health and medical research.

Section 1: Health Consumers- patients, carers, families, and communities

I suffer on, I reschedule, and have to cancel due to the cost.

Respondent to HCNSW/NCOSS cost of healthcare survey 2020

Equitable and Accessible Patient Centred Care

Health Consumers NSW welcomes this review into the funding of health services in NSW. Current funding models are resulting in unnecessary death and increased burden of disease on many people in NSW. With many health consumers having to choose between accessing much needed healthcare or some other necessity.

The costs of healthcare put many families in precarious situations. The cost of housing, running a car, and purchasing food, are being weighed against the cost of needed surgery (in the private system), paying for scans and tests, private health insurance, and the ongoing cost of medications. These dilemmas are magnified for families who have multiple members with health challenges. These families are facing both increased costs but also the awful dilemma of having to decide which family member should receive healthcare in preference to others. Some parents and carers are delaying treatment for their own health conditions, to ensure that their children and the people they are caring for can receive treatment.

Out of pocket costs of healthcare

In 2020 HCNSW partnered with NSW Council of Social Services (NCOSS) to investigate the experiences of people who are struggling with out of pocket costs for healthcare [3]. This work complemented *the Mapping Patient Experience and Economic Disadvantage in NSW* research NCOSS produced in partnership with the National Centre for Social and Economic Modelling (NATSEM). Mapping Patient Experience and Economic Disadvantage in NSW captures the extent to which people in NSW struggle with engaging with health services. It revealed the challenges that different groups, especially people who are unemployed, lone parents and those living in regional NSW, have with accessing health services [4].

The findings of this work give insights into the financial pressures that people living in economic disadvantage face when trying to access healthcare.

General Practitioners

The value of an ongoing relationship with a good, affordable GP who knows you and your health conditions is very important to many people who answered the survey:

The outcome [of my diagnosis] was positive and the complications were managed by my GP who organised a GP Management Plan

My son is lucky to be able to access a Headspace GP.

People reported difficulty finding a bulk billing GP. Many people are worried about not being able to afford a GP who does not bulk bill and the reduction in quality of care that comes from not having an ongoing relationship with a GP who does not know them or their medical history:

When my sons turned 18 the family GP they saw stopped bulk billing them.

My GP does not have a complete picture of my heart health.

I'm about to run out of scripts and I have no idea what to do as I cannot afford a GP or risk seeing someone who may not understand my complex mental health and trauma needs.

Specialists

Likewise, when it came to specialists, people had difficulty in finding specialists who bulk bill:

We could not find a cardiologist who would bulk bill.

No ENT (ear nose and throat specialist) in NSW bulk bills.

I need to see an eye, ear, throat surgeon ... but I have never gone to see him because it is too much money for me to see a specialist who doesn't bulk bill.

I do not have any money to see an immunologist or continue testing and treatment with the specialists.

Some people were unable to access specialists at all, while others reported stopping or restricting treatment because of cost:

I started treatment with a private dermatologist. I have been unable to continue due to the costs.

We did not attend many follow-up specialist appointments [for our son] because of the out of pocket costs.

Dental Care

The cost of accessing private dentists, and the waiting lists for public dental services, has put dental treatment out of reach of many people:

I need urgent dental care and can't afford it. I have avoided going to the dentist due to cost.

All of my children and I neglect our teeth due to lack of access.

Dental treatment is recommended for people with my conditions as we are more susceptible and dental hygiene is imperative. None of this is subsidised and is totally out of reach.

Very few people spoke about using the public system, and those that did had experienced long waiting times:

I can only see the dentist about every 4 years because I need to wait on the public waiting list.

Medications

The cost of medications was another difficult area for many people, who are either going without or limiting purchased medication:

There are fortnights when I have to decide which medications I go without, as I don't have sufficient funds to cover all of the different types of medications.

A further complication was experienced by people who were prescribed medications that are not on the Pharmaceutical Benefits Scheme (PBS):

I require nuanced, tailored treatments that often involve non-PBS medications, which costs \$70 per month or \$140 on extra dosage.

Scans and Tests

People are putting off scans and tests due to costs:

I have to shop around to find scans that bulk bill.

I had to have a MRI [Magnetic Resonance Imaging] on my right knee, I did not have the money to be able to pay for it. My leg has got worse and impacts on my work and my ability to get around.

People reported that waiting time were reduced by getting scans and tests from private providers. The option of having scans or test done by private providers is out of reach for many:

I have had to delay getting a gastroscopy as I was unable to afford it privately and therefore had to wait over 6 months while experiencing ongoing reflux.

I was to undergo colonoscopy & endoscopy procedures and was delayed as I was told I need to pay for the private hospital.

Patients are confused about which scans and tests are bulk billed, and which are not. People report that some scans are bulk billed if they are referred by GPs, while they must pay for the same scans if they are referred by a specialist. The costs associated with visiting a GP for a referral, as discussed above, makes getting such referral difficult. People also report 'bill-shock' on receiving an unexpected invoice at the conclusion of a scan or test.

Not receiving recommended tests and scans put people at increased risk of late diagnosis of a range of important and potentially life-limiting health conditions.

Multiple health issues and multiple health costs

People experiencing economic disadvantage are at increased risk of multiple chronic health conditions [5]. This means people are faced with increasing out of pocket costs from multiple healthcare providers. Meeting all these challenges requires making difficult decisions deciding which condition is prioritised for treatment:

I live with mental health issues as well as type 2 diabetes, osteoarthritis, and sleep apnoea.

I am a survivor of DFV (domestic and family violence) and now as a consequence have complex lifelong chronic physical and mental health injuries. These require nuanced, tailored treatments.

Our son was diagnosed with reflux and it was recommended we see a paediatrician. Over the next 6 months, our paediatrician referred us to a gastro paediatrician, dietitian, speech pathologist, ENT surgeon, paediatric allergist, hearing test and blood tests.

More than one person with health concerns in the same household

Many people are living with family members who also have chronic and complex health conditions. When faced with the dilemma of only being able to afford care for one person, parents and carers are prioritising their children's and partner's care over their own:

I have to prioritise my son's health and wellbeing. He has several disabilities and I ensure that he never misses out on the specialist and allied health services he needs.

I have four sons who always got priority over my health needs.

I would estimate over the course of the first year after my son's birth, we spent more than \$6,000 on medical and related costs. Significant for a family dealing with the other costs of caring for a baby as well on reduced income with one parent not working.

I have had to delay appointments and also choose what child needs to see the specialist most because the cost for all three to see her on one day was more than a week's wage.

Private Health Insurance

Many people felt that they would have received better healthcare if they were able to afford private health insurance:

Since I did not have private health insurance, I cannot afford it, I was denied [treatment in a] private hospital.

I have no private health insurance, so the physiotherapy for my son has been postponed indefinitely.

The cost of private treatment can be prohibitive.

For some, having private health insurance resulted in better care:

My son's assessment cost over a \$1,000. If his partner was not in a health fund he would not have been diagnosed and would not have treatment.

Yet for some people having private health insurance still meant healthcare was too expensive to access:

I have full top health cover but was fearful of the out of pocket costs that I might accrue.

My health insurance didn't pay enough and I had to put it off.

The medical insurance paid for my medical bills and it was a long wait

Despite having private health insurance, I don't see my dentist.

Precariousness

Many of the issues reported here, especially the interactions between different aspects of people's lives, showed the precariousness of many people's situations. People living in precarious circumstances "have lives dominated by insecurity, uncertainty, debt and humiliation" [6].

People living in precarious circumstances are often not eligible to receive pensions, Health Care Cards, or other supports and services. Without these supports, one life challenge (such as a health scare, loss of job, eviction, or relationship breakdown) can impact negatively on all aspects of their lives. People in precarious circumstances often do not have the financial and other resources to bounce back from such challenges.

We strongly urge the Special Commission to consider funding reforms that do not shift the financial burden of receiving healthcare directly to health consumers.

New Technology

Health consumers are, generally, supportive of new technology that:

- Improves their access to healthcare,
- improves their experience of healthcare,
- is convenient,
- reduces out of pocket expenses, and
- has a clear public good.

Consumers and community members are concerned that the cost reduction is the main motivator for introducing new technologies. People in rural areas, while generally welcoming the convenience of innovations such as telehealth, are concerned that developing telehealth and virtual care, will be used to justify defunding other much needed local services.

Telehealth and Virtual Care

Ultimately, health consumers want quality care that is safe and never compromised – regardless of how it is delivered.

Navigating Telehealth: the patients' perspective, HCNSW 2021

In 2020 health consumer leaders raised their concern about the lack of consumer and community participation in designing the introduction of telehealth during the pandemic. HCNSW responded by surveying and consultation with our members to find out their experiences of using telehealth, and their views on consumer involvement in designing new virtual health services.

There is no doubt that for countless patients, families, and carers, gaining easier access to telehealth was a tremendous boost. However, there were also many lessons to be learned from health consumers who reported poor or mixed experiences. Some of the problems are specific to telehealth, such as hardware, software and the skill and confidence of the participants to manage the interaction. Many other issues, however, are legacies shared with face-to-face interactions including concerns with communication, information sharing, co-ordination of care, timely treatment, respecting patient preferences and waiting times [7].

HCNSW believes that the introduction of new technology will not, in itself, lead to improved outcomes and experiences. We caution the introduction of new technologies that are not

accompanied by corresponding investment in appropriate, staffing, training, and education for both patients and clinicians.

Increased access and convenience

The increased convenience of telehealth was the main benefit identified by more than a third of respondents. People in rural areas appreciated the reduced travel time and related expense, and people living with mobility restrictions or chronic pain valued being able access healthcare without exacerbating their condition.

I am someone with chronic pain and fatigue ...<and> a compromised immune system... Sometimes I am unable to leave my house due to pain and/or fatigue.

Respondent to HCNSW telehealth consultations, 2021

Increased effectiveness

Reduced time spent on waiting lists has been a positive spin-off for some patients. For others, the immediacy and ease of a phone consultation means they are more likely to seek care early, rather than wait for symptoms to worsen.

Having access to a blend of telehealth and face to face consultations received high levels of satisfaction from patients and families.

Telehealth can be a tool to encourage and support multiple health professionals coming together with their patient and family at the same time, to better co-ordinate care within and across specialties; and as people move into different health environments.

Reduced access

For some consumer telehealth made it more difficult to access healthcare. In July 2020 a condition was added by the Commonwealth that meant most patients could only use telehealth if they had had at least one face to face consultation with their GP in the previous 12 months. This rule created problems for long-standing patients of GPs who were otherwise healthy and infrequent consumers of their GP's services; healthy people who have not had the need to invest in a long-standing GP relationship; people seeking one-off specialty health services, such as sexual health; and other vulnerable groups who for a range of reasons do not have ongoing relationships with GPs.

Digital Divide

Not being able to access reliable technology is the main reason why many people are unable to use telehealth. People experiencing economic disadvantage are less likely to have access to the required technology, and adequate data plans. Many people living in rural, regional, and remote NSW reported on the unreliability of the mobile network in many parts of the state.

Young people and telehealth

In 2022, HCNSW consulted young people about their experiences of health services during the pandemic. This project, called *Walking the Talk*, was a partnership between HCNSW and the Association for the Wellbeing of Children in Healthcare (AWCH).

We were surprised to learn that young people reported similar ambivalence towards telehealth and virtual care as other members of the community. While the convenience of telehealth was appreciated, young people reported that telehealth was not always user friendly for them. They also reported feeling a lack of connection with health providers they had only met virtually [8].

Data Sharing and Data Linkage

In recent years there has been an increase in projects and research sharing data for system improvement and research. There is evidence that Australians are supportive of their deidentified health data being shared if it will result in a clear public good, such as improving safety and quality of health services, or developing more effective medications and treatments [9].

People are concerned, however, that the sharing of health data is happening without their knowledge or permission. Participants of citizens juries held to investigate attitudes to sharing government health data with private industry reported that they are supportive of data sharing, provided there are adequate safe guards for privacy and security, and that there is accountability and transparency around who data is being shared with and for what purpose [10].

There are number of initiatives within NSW Health that link different datasets for system improvements and improving health outcomes. While these are achieving good results HCNSW is concerned that there is not enough public awareness about these activities. Inadequate attention has been paid to building public and patient awareness about these projects. There is an assumption in some areas that the community is supportive of this work because of the public good it generates. However, a community license cannot be granted when the community is not aware of how their data is being used. Without a community license there is a risk that this, and any future data linkage work, could be undone by loss of public trust.

Children and Young People in healthcare

According to the Australian Institute of Health and Welfare, it is estimated that 7.5% of children and young people are living with a disability and 10-20% of children and young people are living with a chronic illness. In NSW, as with the rest of Australia, most children and young people receive care outside of specialized children and young people hospitals and other healthcare services. There is a desperate need for the system to resource these services to ensure that children and young people receive developmentally and age appropriate, safe, and supportive care. Access to play, education and having a say in your healthcare are basic human rights that are often denied to the over 25% of children and young people living with chronic illness and disability in NSW. Resourcing allied health is also a particular issue given the time sensitive nature of intervention for children, with far too many waiting unacceptable time periods for treatment and support, putting them on a trajectory of difficulties with school, learning and peer relationships with serious consequences into adolescence and adulthood.

Transition from Paediatric Care to Adult Care

A huge area of need with the paediatric and adolescent populations with chronic illness and disability in NSW is transition from paediatric care to adult care. This time in young people's lives is often extremely complex with multiple intersections occurring and when young people do not receive age and culturally appropriate care it again sets up a negative trajectory for their future health and wellbeing. There is good evidence that shows that health and wellbeing outcomes often reduce once a young person leaves a paediatric service and moves into an adult service and demonstrates the need for more youth and young adult services as well as the upskilling of adult healthcare in the appropriate and effective care of young people.

Use of volunteers to assist health professionals is greatly under resourced and underutilized and proven programs like the Association for the Wellbeing of Children in Healthcare (AWCH) *Ward Grandparent Program* struggle to resource programs that support children, young people, and their families as well as support staff to provide excellent care.

Section 2: Consumer and Community Engagement

There is strong evidence that meaningful engagement with health consumers and community members across health systems, policies, services, and research leads to improved health outcomes, better patient and carer experiences, and safety and quality improvements.

The engagement and involvement of local communities in health service development and delivery.

The explicit mention of the engagement and involvement of *local communities* in the terms of reference for the Special Inquiry is welcome. HCNSW is, however, disappointed that there was no explicit mention of engagement with patients, carers, or health consumers in the terms of reference. This omission is indicative of language used to exclude and minimise the unique perspectives that health consumers bring to engagement processes, as reflects the misunderstanding, and missed opportunities, that arise from confusing community and consumer involvement.

What is Consumer Engagement?

Consumer engagement is used, in this submission, to mean a specific set of practices that involve health consumers participating in health service decision-making, policy development, service design, delivery, and evaluation [2].

Consumer engagement supports the design, delivery, and evaluation of health services. The involvement of people who use health services (health consumers) helps improve existing services and adapt to known health needs. Consumer engagement contributes to improving consumer centred care by recommending improvements to services and providing a better understanding of the consumer journey.

The involvement of consumers in their own care and in the delivery and governance of health services is enshrined in the National Safety and Quality Health Service (NSQHS) Standards. NSQHS Standard 2, *Partnering with Consumers*, explicitly outlines the expectations that health services are required to meet in this regard [11].

Consumer representatives and engagement staff within NSW report that that this standard is one of the main enablers driving development of consumer engagement in NSW Health.

Community Engagement

Community refers to groups of people or organisations with a common local or regional interest in health. Communities may connect through a community of place such as a neighbourhood, region, suburb; a community of interest such as patients, industry sector, profession or environmental group; or a community that forms around a specific issue such as improvements to public healthcare or through groups sharing cultural backgrounds, religions or languages [2].

Community Engagement refers to the set of practices and policies that bring members of these communities that health services serve into the decision making and governance processes.

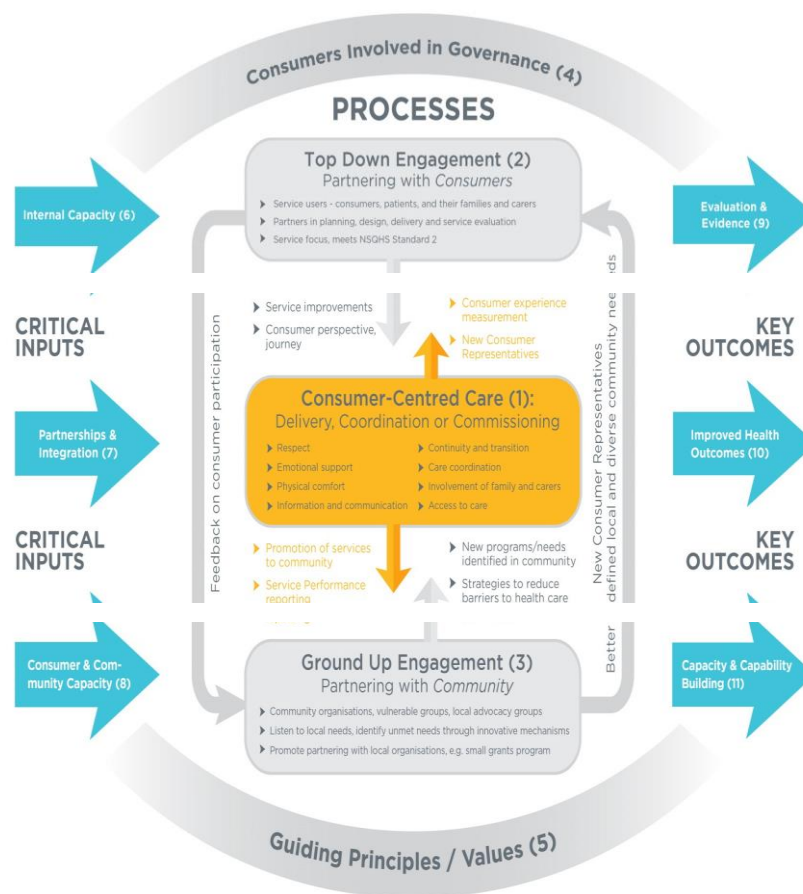
Community Engagement identifies gaps in services, access issues and other unmet needs. Partnering with community organisations or engaging widely with diverse groups also allow communities to help identify strategies to reduce barriers to their healthcare. Community groups and health services can, together, identify and act on emerging health issues and gaps in service delivery.

HCNSW Consumer and Community Engagement (CCE)

Engaging with *both* health consumers *and* community members are needed to improve patient centred care. Each group provide different and complementary intelligence and guidance.

Health Consumers NSW and WentWest (Western Sydney Primary Health Network) have developed a consumer and community engagement model to assist services better understand these differences between consumer and community engagement [2]. The model is designed to assist services map and plan their consumer and community engagement (see Figure 1).

Figure 1: The Health Consumers NSW/WentWest Consumer and Community Engagement Model



Source: HCNSW / WentWest Consumer and Community Engagement Model [2]

The aims of the Consumer and Community Engagement Model are:

- to improve consumer centred care;
- to work collaboratively with community to identify the unmet needs of Australian communities; and
- to build the capacity and capability of health consumers to participate in the design, delivery and evaluation of their healthcare [2].

Consumer and Community Engagement across NSW Health

In 2018 Health Consumers NSW was commissioned by NSW Health to assess and review consumer and community engagement across the health system. We found that while all LHDs and most Pillars had implemented policies and structures for consumer engagement (to varying degrees of maturity) there was no system wide structure that brought consumers together to share experiences and contribute to statewide planning and policy development.

This needs assessment for CCE in NSW Health recommended the development of a statewide consumer body. We are pleased to have been consulted on the development of the proposed *NSW Consumer Council*, as part of the governance structures of the Future Health Strategy. This council will be part of the governance structure of Future Health Strategy, and we welcome it as a first step in building a robust statewide CCE infrastructure. We hope that this body, once convened, will be involved in making decisions on how to build the CCE infrastructure within NSW Health.

Bringing Health consumers and community members into healthcare governance

Including health consumers on hospital and health service boards has been shown to have numerous benefits for both consumers and health services.

Research has found that involving patients in hospital governance can lead to improved patient satisfaction scores. The involvement of consumers and community members in governance structures at all levels can provide:

- valuable insights into the needs and perspectives of patients,
- a focusing on patient safety,
- insight into improving patient experience,
- advocate for patient-centred care,
- bring attention to issues that may otherwise go unnoticed, and
- ensure that decisions are informed by patient and community standards

Including consumers and community members in local governance structures can help build trust and credibility with the community. Patients are more likely to trust an organisation that involves them in decision-making processes, leading to increased patient loyalty and better community relations.

In addition to these benefits, patient involvement in health service governance can even lead to improved financial performance. There is growing evidence that consumer input helps health services make better decisions regarding resource allocation and cost management.

Care must be taken to ensure the safety of health consumer appointed to Boards. In addition to lived experience of being a patient and/or carer, people appointed should, of course, also have knowledge of their governance responsibilities. Appropriate training, mentoring and support needs to be available to consumers, Board Chairs, CEs, and staff supporting the Board.

Boards should also have members with expertise in consumer engagement. Knowledge and experience in creating the infrastructure and processes needed to involved consumers and community members in the design, delivery, evaluation, and governance of the service is different to, and complementary from, the expertise and lived experience that health consumers bring.

Overall, including health consumers in healthcare governance can have a significant positive impact on healthcare organisations. It ensures that the needs and perspectives of patients and carers are considered, builds trust and credibility with the community, and even improves financial performance.

Involving consumer and community members in governance is a relatively simple way to bring a level of accountability and transparency to health services. It ensures that councils and boards remain focused on patient safety and patient experience, and that decisions reflect community standards and expectations.

Sustainability of current Consumer and Community Engagement processes

During the early stages of the COVID-19 pandemic, HCNSW observed that local mechanisms for engagement with consumers and community members fell away. NSW Health quickly implemented a new structure to coordinate the local pandemic response. The participation of consumers was noticeable by its absence in this response. In facing the unprecedented crisis posed by the pandemic the system defaulted to a traditional 'command and-control' and biomedically centred healthcare.

Consumer leaders approached HCNSW about this and in April 2020 we formed the COVID-19 Consumer Leaders Taskforce, followed soon after by the COVID-19 Consumer Organisations Taskforce, to advise HCNSW on the experiences of consumers and consumer representatives during the pandemic. We partnered with the Australian Centre for Health Engagement Evidence and Values (ACHEEV) at the University of Wollongong to document and analyse consumer leaders' experiences during the early days of the pandemic.

The research found that where active consumer participation was maintained, it was due to individual leaders or 'champions' in health services, rather than a systemic trend. Consumer representatives were willing to step back and allow health services and clinician groups to respond to the crisis at its peak. Consumer representatives were willing to forgo their involvement in decision making and governance for less participatory activities (such as information sharing and consultation) when the pandemic was perceived to be a short-term emergency. However, continued exclusion as the pandemic progressed impacted the trust that consumer representatives had in the system and their place in it. Yet, in a remarkable demonstration of proactive self-organization, consumer representatives developed alternative approaches to effectively bring patient and community voices into pandemic-impacted service design and delivery. This was driven by the monumental shift in how the system was operating in a healthcare crisis that left a vacuum in place of previously structured, albeit inconsistent, consumer participation. The pandemic was a fluctuating and turbulent event that loosened previous interconnectedness between consumers and the healthcare system and 'released' the energy and momentum for consumer representatives to rapidly adjust and reorganize alternative forms of influence.

In the absence of developed structures or plans to involve and integrate consumer representation in a pandemic of the scale of COVID-19, there was room for consumers to drive and determine the shape of their input in pandemic-related issues. The result was that the pandemic triggered a key transformation of innovative consumer participation. The opportunity to resort and reorganize ways of working in the health system created new opportunities for consumers to initiate and trial alternative ways to participate.

The pandemic revealed just how 'brittle' local CCE processes are. The processes shattered just at the time when they were most needed. Despite this, consumer representatives were able to organise and continue to influence the system [12].

Building the Consumer Representative Workforce

The growing number of consumer representatives working within NSW Health needs to be recognised as part of the workforce. Consumer representatives are involved in hundreds, possibly thousands, of health service projects. They are members of standing committees, as well as short term project and policy committees classed as 'volunteers' by some NSW Health agencies, and as 'contingent workers' by others. NSW Health does not know how many people are involved in various engagement activities across, nor does it know the demographics of consumer representatives. There is no base line number to measure effectiveness of current engagement strategies, nor the attempts to diversify the consumer representative workforce.

Investment in this workforce is long overdue. There is no consistent requirement for training or education of consumer representatives. HCNSW has recorded a reduction in the number of consumer representatives receiving our training in recent years. There was a marked decline in training during the pandemic, but we are yet to return to pre-pandemic levels.

Patient Leaders / Patient Directors

Health Consumers NSW is advised in much of our work by experienced health consumer leaders. People with not only lived experience of using health services, but also skilled consumer advocates and representatives who understand the working of health services and systems.

The role of consumer leaders needs to be acknowledged and strengthened. We support the ideas of David Gilbert, patient advocate and thought leader from the UK. Who advocates for the introduction of paid patient leaders and patient directors, at executive levels in health services [13].

Resourcing for diversity in consumer engagement

Health Consumers NSW has identified challenges involving people from diverse communities in consumer engagement.

Young people (14-25 years of age) face significant barriers to accessing timely, quality, patient-centred care. These include ageism within the system, financial barriers, structural barriers, and attitudinal barriers. These issues are exhibited in the white paper and final report of the 2022 Walking the Talk project, led by HCNSW and the Association for the Wellbeing of Children in Healthcare. It is essential that young people are supported to have influence in the design, delivery and evaluation of health services, programs and policies [8].

Reimbursement and Remuneration of Consumer Representatives

Health Consumers NSW recommends that consumers invited to engage with health services, research institutions, and other health entities, be remunerated for their contribution and reimbursed for expenses. At the very least consumers should not be out of pocket for their involvement. We have developed guidelines for remuneration and reimbursement of health consumers in both health services [14] and in research [15].

Paid participation recognises the value of the expert contributions made by people who have a lived or living experience of being a health consumer. It also lessens the financial barriers some people have when it comes to engagement. People experiencing economic disadvantage report that they are often unable to participate in engagement processes (such as attending a committee meeting) due to costs associated with travel, parking, access to technology, or organising care. Engagement activities held during working hours also mean that some people must take time off work or even forgo income (if self-employed or in casual employment) in order to participate.

“It supports diversity in consumer advocacy. Otherwise it’s only those that can afford to volunteer do [get involved], and we need as many voices as possible.”

Respondent to HCNSW remuneration survey 2023

In April 2023 NSW Health released guidelines for remunerating and reimbursing consumer representatives [16]. HCNSW welcomes these guidelines, the rates are slightly less than HCNSW recommendations but are a good starting point. We are concerned that the guidelines are voluntary and are being introduced unevenly across the state.

Health Consumers NSW surveyed our members on the release of the NSW Health guidelines. We found that most people are not receiving (or have been offered) remuneration. There is also confusion around the difference between remuneration and reimbursement.

Remuneration - Payment for the participation in and contribution to an engagement activity.

Reimbursement - The repayment of costs associated with participating in the engagement activity.

Consumer representatives, overall, appreciate being offered remuneration. 85% of respondents to our survey said they would accept remuneration if it was offered to them.

Some consumer representatives choose not to receive remuneration. For some it is because they view this contribution as part of their volunteer work, for others receiving remuneration would complicate their Centrelink, taxation, or Superannuation arrangements. There is much contradictory and confusing information about the impact of paid remuneration on these payments, and consumer representatives report difficulty in finding expert advice on what receiving such payments would mean for their own circumstances.

The survey revealed that many consumer representatives are out of pocket because of their engagement work. We were very concerned to learn that many consumer representatives not offered reimbursement for the expenses they incur for this work, these expenses include parking, travel, carer support, printing, childcare, and respite care.

[Involving consumers and community members in solving ‘wicked’ problems](#)

Health consumers and community members are often excluded from decision making when issues are seen as too complex or too sensitive. These are precisely the times when consumers and community members should be brought into discussion. Consumer representatives can ensure that the vital issues of patient safety and patient centred care, remain at the forefront of decision-making. Community members can play a vital role in ensuring that decisions reflect community attitudes and expectations.

Health Consumers NSW has partnered with ACHEEV and WentWest in running citizens juries. This participatory methodology brings together representative members of a community to deliberate on a complex ‘wicked’ problem (such as the sharing of health data for research). This process always yields thoughtful and nuanced solutions to issues that experts and advocates have often grappled with for years. It is a methodology well suited to finding solutions to problems like how to increase the ranges of services offered in rural communities, implementing technological solutions while allaying community concerns about privacy and security.

The advantage of Citizens' Juries is that they bring community members into the decision-making process around difficult issues that the public often does not have a good understanding of. Through the process jurors learn more about the topic and devise solutions from the perspective of members of the public who have no particular 'axe to grind' who can examine the issue with disinterest.

We recommend that the Special Commission investigate the use of citizens juries, and other participatory methodologies, as ways to generate advice for government and health services on how to implement the more complex recommendations of the Special Commission.

Section 3: Systemic Issues

Health System priorities – capital works v. prevention

This is really dire, you know, and continuing just to pump money into capital works and build up more hospitals, that they can't even staff is ridiculous.

Consumer leader consultations, 2023

Consumer leaders report their frustrations around the building and rebuilding of local health facilities, which are often opened with much fanfare, and then not being enough staff to operate the service. Members of HCNSW and health consumers leaders would like to see greater investment in health prevention. In 10 years time our members would like to see less hospitals being built, because they are not needed.

Health Consumers NSW would like to see greater investment in prevention and strengthening community connectedness. Our members would like to see a greater understanding of the social determinants of health. And, ultimately, a move away from building more hospital and opening hospital beds, and a greater investment in primary and community health. This would include strengthening community based NGO providers and health consumer organisation that provide information and support to health consumers.

Navigating increasingly complex systems

The increased difficulty in navigating the healthcare system is a common theme from all the consultations and discussions with health consumers (patients, carers and families) we have held over the years. HCNSW is a partner with initiatives and research projects that are working to create more coordinated and better integrated care. All these initiatives are welcome but will take time to implement, and most are only going to be effective within a particular service, or at a very local level.

I felt like a tiny person in front of a massive skyscraper.

Participant, Walking the Talk, youth experience and engagement project, 2022

Peer workers

Many mental health services engage peer workers to provide support to clients. Peer workers are people with their own lived experience of mental health challenges, they connect with clients and can provide information and support around treatment and recovery. Some peer workers also help connect clients with other relevant health and community services.

The model of peer workers is well entrenched in mental health services. We believe the model could be expanded beyond mental health to work with people with a variety of health conditions.

Care Navigators

The introduction of more care coordinators and health navigators would be a very cost-effective way to assist people to navigate the increasingly complex health system. People with chronic health conditions often have to interact with multiple other systems (such as aged care, disability services, NDIS, education, and housing).

Health navigators could assist connect people with relevant local health and community services. Navigators could also help people access services they might not otherwise know about, as well as promote health literacy and healthy behaviours. Models for care navigators exist in other jurisdictions and could easily be adapted and introduced in NSW. Care navigators have been found to improve health outcomes for vulnerable people, reduce readmission rates to hospital, increase people's health literacy, and reduce risk factors, such as loneliness and social isolation.

Workforce Culture

I hear constantly that people are overworked, and the health services are overworked. And I hear that we can't get people, but they still will not call out poor behaviour, and poor culture, which is driving people from our hospitals.

Health Consumer Leader 2023

Item F in the terms of reference for the Special Commission have a focus on creating a sustainable healthcare workforce. While the issues highlighted within the TORs are all important to achieving these aims we believe a greater focus on workforce culture within health is also needed.

The workforce issues of NSW Health will not be addressed if the poor culture of some services is not changed. Consumers and consumer leaders have told us of instances of bullying, rudeness, and discriminatory behaviour from staff. Such behaviour is not only directed towards patients from staff but also to other staff, especially junior staff. Patients and families witness this behaviour, which sometimes comes from senior clinicians and leaders, and worry that 'if you can't take care of each other how can you take care of us?' Greater emphasis needs to be given to not only to promoting kindness, but to also eliminating bullying, stigmatising, and disrespectful behaviour.

Consumer leaders also report instances where they have observed high staff turnover as a result of poor culture. Making it more difficult to adequately staff services, especially in rural and remote areas. We believe that increased accountability and transparency is one way to improve behaviour that is unnecessarily tolerated. We recommend that consumer leaders be involved in staff reviews and investigations into poor staff behaviour, especially when this involves senior staff.

Funding models- activity based funding v. equity based funding

Current funding models inequitably distribute resources away from where they are most needed.

In recent years we have seen a shift away from equity-based funding to activity-based funding. The previous model of equity-based funding was designed to ensure local LHDs or specialised NGOs were resourced to support different populations and conditions, based on the demographics of the local area. These programs often incorporated a rating for rural areas. This model was designed to provide adequate services based on where patients live and where people choose to access health services.

The move in recent years to activity-based funding and managing through key performance indicators (KPIs) has reduced specialist services and put vulnerable populations at risk. This has decoupled the link between funding and achieving positive outcomes for patients and communities. Conversations with people living with HIV reveal that 9 people have recently died from AIDS in Liverpool hospital, due to a lack of specialised local services being able to offer care and support to local vulnerable communities.

We need to return to funding models that look at the needs of disadvantaged and marginalised populations, and developing and funding local strategies and services that respond to local need. The current NSW Health structure has increased the autonomy for LHDs but at the expense of the Ministry of Health being able to direct how LHDs should use their resources to meet the needs of local patients and communities.

HCNSW is supportive of local services and districts being able to adapt their services to meet local conditions. This is required to ensure that local health services are able to contribute to closing the gap when it comes to Aboriginal health, and that health services in rural, regional and remote areas are able to respond to the recommendations from the *Parliamentary Inquiry into Health Outcomes and Access to Health and Hospital Services in Rural, Regional and Remote NSW* [17].

We believe, however, that the current structure needs rebalancing to better meet the needs of the most vulnerable patients and communities.

Glossary

ACHEEV	Australian Centre for Health Engagement Evidence and Values, University of Wollongong
AWCH	Association for the Wellbeing of Children in Healthcare
CCE	Consumer and Community Engagement
GP	General Practitioner
HCNSW	Health Consumers NSW
LHD	Local Health Districts
NCOSS	NSW Council of Social Service
NSQHS Standards	National Safety and Quality Health Service Standards

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