



Consumers Health
Forum OF Australia

Response

**Discussion paper and draft
recommendations from the
Primary Health Reform Steering
Group**

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Consumers Health Forum of Australia (2021)
*Response to discussion paper and draft
recommendations from the Primary Health
Reform Steering Group. Canberra, Australia*

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Introduction

The Consumers Health Forum of Australia (CHF) welcomes the opportunity to respond to the discussion paper and thanks the members of the Primary Health Reform Steering Group for the invitation.

CHF has long reflected the views of members and consumers, advocating for a system that places the consumer at the centre of care, with linked services that focuses on the health and wellbeing of the whole person. To frame our response to the discussion paper CHF hosted a webinar to help our member organisations and consumers better understand the context of the reforms and the practical benefits recommendations proposed by the Primary Health Reform Steering Group and held follow-up consultations.

I want primary care that recognises and uses the knowledge and experience I have managing my condition.

While CHF supports the recommendations made in the discussion paper and, in particular, the need for reform of the primary health care system and funding model, to achieve that goal, there should be greater focus on placing consumers at the centre of that system and model. In consultations about the discussion paper and its recommendations, consumers were very clear about two things:

1. The most important areas of reform – and the priorities for consumers – are encompassed by recommendations 6 (empowering people, families, carers and communities), 7 (comprehensive preventive care) and 8 (improving access where needed and for people at risk). There was also strong, but qualified, support for a one system focus, with concerns that it could turn into another system, designed by experts, into which consumers would need to fit, unless co-developed and maintained in partnership with consumers. This highlights the importance of involving consumers in regional governance of primary health care change.
2. Care needs to be taken to make sure that the reforms do not create just another system developed by interest groups and experts. While these groups and people may believe they understand consumers and are developing person centred care, consumers must be equal partners in developing the systems that affect them, and in helping other partners to understand their health experiences and journeys.

Issues

CHF members and consumers identified priority areas for reform of primary health care, as well as concerns with the discussion paper and recommendations, including:

- the need for consumers to be given more power, agency and autonomy to make their own choices of health care providers, to be able to easily change providers, and to not be constrained by registering with a single provider
- support for increasing health literacy and consumer involvement in navigating the health system

- just like the health workforce, consumer advocates should be supported, developed and have access to leadership development and training opportunities
- that while the recommendations extend primary health care to consider areas that are currently outside the system, such as the social determinants of health, other areas have been left out, including dental/oral health and the effects of climate change, as have out of pocket costs that limit access for consumers, for example in allied health care
- that integration should not be confined to how primary health operates as a system, but how it integrates with other parts of the health system, including specialist and hospital care, aged care and disability services.

One thing that makes it really hard is that disability and health have such an enormous mutual incompatibility and neither side have the faintest idea how to help with the other side, and there's a huge gulf in the middle that's not covered.

I got a pressure sore when I was in hospital last year, I needed an alternating air mattress. because I'm bedridden 24/7 – this was a HUGE BIG DEAL. Because I'm on NDIS, it was an NDIS funding deal.

No kidding, my GP said, "You should really get it today", and just thought that NDIS would make it happen magically THAT DAY.

Consumer priorities

Consumers support an integrated system of care and a funding model, that places wellness and whole of person care ahead of just treating each illness or medical condition. They would like to have access to a coordinated, multidisciplinary health care team that places them at the centre of care, gives consumers – patients, carers, families and communities – the information that they need to maintain their health and wellbeing, and to be active participants in their own care and treatments when they are sick.

For prevention, if you can make that work with a single destination where they are giving a more overall view, rather than just dealing with the crises as they arise, hopefully that does give you better prevention because the GP will see it as part of keeping you healthy.

CHF members and other consumers prioritised the recommendations related to integrated, person centred care and their engagement in health reform. However, they wanted a greater emphasis on the delivery of evidence-based prevention and an expansion of the

The tone is system centred not patient centred.

I get to choose someone and that person takes on the power. We're scared we're going to have less power, not more.

recommendations to include areas of health that are outside of the existing primary health care system, including dental health, palliative care and social determinants of health.

Many consumers felt that the statement of value of health care to them, and what they would like to be able to say about the system in ten years' time does not reflect an equal partnership in co-managing their health care needs, or their need to have confidence in their practices and in the system. There were many specific suggestions to improve the language – they want to collaborate, not be supported; to own their own records, not just given access to them; to be informed about evaluation and how their responses to feedback options like PREMs and PROMs are used for service improvement, not just asked about their experiences; and they want clear mechanisms and pathways to resolve concerns and complaints.

The assumption that you can co-design for chronic illness as though it's just one thing, or for people with disability as though they were one cohort, has them very worried that the changes will still leave them marginalised by the health care system yet again.

Recommendations 1 to 8: An integrated system for person centred care, building better experiences and outcomes

While consumers generally support an integrated system and new funding models such as collaborative commissioning by PHNs and LHNs, they raised concerns about introducing a model of voluntary patient registration if it were to limit consumer choice in their own care.

Palliative care is integrated with primary health in the country I come from. I find it really hard that you move into palliative care and then your GP is of no use. Your GP cannot come to your place, or come at night if you need them to – they are not involved any more.

There is no mention of voluntary assisted dying – for a plan over 10 years, when voluntary assisted dying will be legal all over Australia by then. It should be part of palliative care as an end of life option and integrated with primary care.

Consumers also identified that an integrated primary health care system designed to keep people well has limitations, for example when it comes to aged care and end of life care.

They were concerned that the discussion paper seemed to focus on a voluntary registration system that, while providing for whole of person health and wellbeing, rather than fee for service treatment of medical conditions and illness, would limit their choices. Specifically, they were concerned that under a voluntary patient registration system:

- a consumer would be required to register with a single practice, limiting those who move frequently, travel, would like a second opinion, may like to go to be registered at more than one practice (for example, seeing a doctor of the same sex or gender for some conditions, but have a preferred doctor for other conditions, or preferring a particular allied or other health practitioner at one practice over another)
- a person with complex medical needs may not be adequately supported with funding to the practice to meet their needs, and that practices will avoid registering patients with high needs
- there may still be out of pocket expenses borne by consumers, that would particularly affect access to care by disadvantaged consumers and communities
- a consumer who cannot get an appointment quickly with their preferred practice, may not be able to choose to occasionally use another practice
- a young consumer may not wish to see use a practice they are registered with by a parent for personal health matters, and not want their parent to know that they are visiting another practice by registering elsewhere
- a rural, regional and remote consumer may not be able to travel to cities or urban centres to access preferred health services when they choose.

There's no mention of care coordinators – support people for people with disability, who don't have health literacy, who can't drive their own care.

Missing from the discussion of integrated primary health care is the need for navigation support to enable consumers and communities to access the information and services they need. Some of the issues of voluntary patient registration with a single practice could, in fact be overcome with navigators who operate across communities, supporting consumers to access the health and wellbeing services they need, including to:

- different practices where appropriate
- allied health and other health practitioners operating across or between practices
- social prescribing for overall wellbeing, for example exercise groups/classes, cooking classes, and social groups
- supports to address social determinants of health, for example housing, the environment, education, and advocacy services.

There is no recommendation for integrating social services – there is no shift in thinking. I feel that it has been conceived by engineers/builders of bygone years, rather than by architects for the future.

Also missing is a discussion of ‘medical neighbourhood’ and describing how general practice teams and other workforces – particularly consultant physicians and paramedics - can work more closely together and offer extended models of care. There are examples of GP-consultant physician shared care but they, and other progressive models, need to be more commonplace and embedded in the system. There is value to coordinated care for consumers for there to be incentives for specialists to work outside of the hospital walls and integrated into GP teams.

Recommendation 9: Leadership and culture

This recommendation was well received by consumers. There was a view that the recommendation could be more “adventurous” and forward thinking, and that thought should be given to including and developing consumer advocacy and leadership.

The leadership and culture can be managed by supporting leadership initiatives that encourage collaboration and are continuous and dynamic, responding to both individual and population needs

Recommendations 10 to 14: Workforce development and innovation

Consumers were concerned at the number of recommendations, with the purpose seemingly to preference some occupations over others. While the specific professional groups are important, consumers considered that the recommendations reinforced workforce silos. Far greater emphasis is needed on workforce development and innovation, not only supply and distribution. Far greater emphasis is also required on action to improve interprofessional education and collaborative practice and embedding a culture of teamwork in pipeline training. It is from team-based care that consumers will benefit most. Consumers considered that a single recommendation, encompassing new and emerging health professions as well as traditional practitioners would be sufficient. Consumers felt that the recommendation should also include consumer representatives and advocates as part of the ‘workforce’.

“Registered health care professionals” could be substituted for any specific position, because we’re trying to create a primary care workforce that has diverse skills and can work across traditional job descriptions.

Recommendations 15 and 16: Innovation and technology

The whole point of reform is innovation in the health care system. The plan needs to take us forward to a health care system that is very different to the one in place now to meet the needs of consumers, and is agile enough to change and adapt as evidence is collected and understood. With innovation such an important ingredient for an integrated health system, consumers suggested that a statement (and possibly the recommendation itself) be positioned at the start of the document.

I appreciate that we are in total lockdown and this is an extreme but if we as consumers push for technology that allows real time testing (this requires the tests and our infrastructure to be upgraded) and meaningful reporting with clear instructions to the consumer as for next steps, it will help combat the epidemic. In doing this, we need to think of the people who are not technology savvy.

Recommendations 17 and 18: Research, data and continuous improvement

CHF has long advocated for research that if focused not only on medical outcomes – the success or failure of treatment and procedures – but that consumers need to be asked about both their treatment and their experiences of the care that they received.

We want data to be captured on unmet needs and for the data to be used to address the needs that patients think are important.

Systems need to be used, not just up to practitioners to decide whether to use – like with MyHealthRecord.

A continuous improvement approach would promote and fund innovative approaches to delivery, while simultaneously collecting evidence, including consumer feedback, to develop and improve services as needed and, just as importantly, share that information with other health services.

Recommendation 19: Emergency preparedness

Consumers identified that emergency preparedness offers a clear demonstration of the extension of primary health care beyond Commonwealth government delivery, and even state and territory jurisdictions, as health and other services are often delivered by local governments and community sector organisations.

We need to recognise the broader people that come in and help us when we're in trouble. They always forget the local government areas. They're so important. As the Mayor of Rockhampton said, they do floods so well because they've done it so many times. And then there's the Red Cross and those sort of things.

This recommendation could be clearer in identifying the types of emergencies included. In CHF's view, emergencies comprise:

- floods, fires, droughts and other natural disasters, especially as adverse weather events become more frequent
- the effects of increasing temperatures, particularly in disadvantaged areas
- more frequent pandemics.

There's no point in just having a plan that is sitting a filing cabinet somewhere, which is what seemed to have happened with the pandemic.

A new primary health care system should recognise the certainty of increasing weather events and temperatures, and include planning for climate change responses.

Recommendation 20: Implementation

A 10 year Primary Health Care Plan must be a living document that is flexible and agile. It must have a capacity to reassessed and adjusted when needed. It should be clear that health primary health care will be co-designed and co-evaluated with consumers, and that consumers will remain at the centre of continual system improvement.

Health pathways are being driven by something called a "subject matter expert", who is unidentified, but definitely not a consumer. No one is asking the person who goes to the health sector with a condition or issue what they are looking for by the service or in the system.

Conclusion

CHF strongly supports a fundamental change to the way that primary health care is delivered. We will be looking for a 10 Year Primary Health Care Strategy that is backed by a clear and transparent implementation plan with milestones and public accountability for implementation. A new system should put the consumer – patient, carer, family member and community – at the heart of care. It should give consumers choices, power and control over their own health.

While the recommendations in the discussion paper set out to achieve those objectives, consultations suggest that further refinement may be needed to satisfy consumers that the new integrated system, as described in the paper, will meet their needs.

The thing that stood out to me is that this is still a system where the patient receives – I'm not picking up any patient power in either being able to say what we want, what we need. It says, "here's the system, we've designed it, and it meets all your needs". There needs to be more focus on giving patients some power so that they're able to clearly express what their needs are, and have them met.

The emphasis on voluntary patient registration arouses suspicion in some consumers, worried that it will constrain their choices. This has been a continued reservation expressed by some consumers across the many years in which primary care reform has been discussed and underscores how vitally important it will be to communicate the value of voluntary patient registration to the community.

Consumers should expect to see a visible difference in the quality and type of care they receive as part of voluntary registration arrangements. At the same time, some felt the recommendations are not adventurous enough, and there was a sense that they were entrenching, rather than further developing, outmoded notions of medical practice.

CHF does not question the importance of general practice and a relationship to a GP. We know from our Australian health consumer sentiment survey that people value having a GP, particularly those with complex and chronic conditions who prefer to have appointments with the same GP. However, we would like the recommendations reflect a greater ambition – and plan – to move to new enhanced models and concepts, for example:

- with practices that share resources or offer different, but complementary services
- with practices that offer a greater focus on wellness, self-care and self-management via integrated primary and secondary preventive health services and advice
- with care navigators and social prescribing link workers who can direct consumers to services, that offer the mix of health services they need, and can help “fill” social prescriptions, as well as offer information to increase their health literacy. A national social prescribing scheme should be a feature of a ‘new system’
- by supporting and funding models of primary care that offer ‘step up and step down’ care. Integrating consultant physicians and paramedics as a valued workforce in the ‘medical neighbourhood’ is required

- by broadening the scope of primary care to include areas of health and wellbeing like dental/oral health care, palliative care, loneliness and social isolation, housing and other social determinants of health, and by addressing costs and affordability.
- by identifying, recognising and addressing emerging threats, such as the health effects of climate changes, and, lastly
- by investing in developing consumer leaders so they can serve as service improvement and development advisers and in regional governance of reforms such as collaborative commissioning. CHF's Collaborative Pairs program an example of a consumer-clinical leadership development initiative that could be scaled to enable this.