Consumers Health Forum of Australia

SUBMISSION

Response to the Productivity Commission Issues Paper for 'The Social and Economic Benefits of Improving Mental Health'

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Response to the Productivity Commission Issues Paper for 'The Social and Economic Benefits of Improving Mental Health' Canberra Australia

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Executive Summary

Australia has a universal mental health system in principle, but not in practice. The Consumers Health Forum of Australia's (CHF) recent consumer sentiment survey coupled with a supplementary lived experience of mental health care survey attest to this. The time to transform the health and mental health system and consider them in a broader societal context is now. Multiple reports and reviews over many decades confirm time and time again that consumers and carers experience a mental health system that is fragmented, difficult to understand and navigate. It is a system that is not serving them optimally.

CHF is pleased to present this submission to the Productivity Commission's *Inquiry into the Social and Economic Benefits of Improving Mental Health*. Our submission is structured around the questions in the Commission's Issues Paper. We make some general comments on the overall scope of the inquiry and offer specific comments in ten key areas. We devote much of our commentary to the structural weaknesses in healthcare and to the major issues for our constituency: physical and mental health comorbidity and the management of multimorbidity. We consider the lived experience feedback received in response to our survey.

Our chief recommendation is that all of the recommendations in the *Contributing Lives, Thriving Communities* report by the National Mental Health Commission be implemented.

Our other recommendations include:

- A COAG-led whole-of-government policy and implementation roadmap for mental health reform with an appropriate and highly transparent monitoring and reporting framework
- Utilisation of Australia's 31 Primary Health Networks (PHNs) as the regional infrastructure to translate and implement national policy by serving stewardship, regional integrator, innovation accelerator and commissioning roles in mental health services
- The establishment of an independent national mental health consumer and carer organisation to strengthen person-centred policy setting and program design as well as investment in consumer leadership development
- Accelerated implementation of stepped care approaches to integrated mental health service delivery on a regional basis led by PHNs
- A major primary mental health care reform effort that would include the introduction of patient and family-centred health care homes in Australian general practice that cater for people with mental and physical health comorbidity; and a redevelopment of the Better Access Program to ensure it is better targeted and digital transformation to strengthen system and care coordination
- An annual report to Parliament and a strengthened reporting and monitoring role for the National Mental Health Commission.

Our hope is that the final report will give impetus to move some of the many improvements mooted in past reviews and reports from idea to reality, accelerate the integration of the general health and mental health care systems, and underpin the necessary transformation of the current system to a patient-centred one.

Introduction

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health consumer affairs. We have around 200 members reflecting a broad spectrum of organisations including state-based consumer peaks, condition-specific groups, volunteer patient groups, professional associations, Primary Health Networks (PHNs) and the research community. We work in collaboration with our members, national partners and research collaborators to influence policy, programs and services to ensure they are in the consumer and community interest. CHF is pleased to make this submission to the Productivity Commission inquiry into mental health.

CHF works to achieve safe, quality, timely and affordable healthcare for all Australians, supported by accessible health information and systems. We support the principles of consumer centred care, a key tenet of which is that consumers must have choice and control over their own health and care[1]. As a national peak with members who speak with authority on their core objectives and members, CHF focuses our advocacy on cross-cutting, systemic issues of interest to all our members. Our chief areas of interests fall into the following five areas all of which touch on policy levers that affect mental health policy, programs and services:

- Safety, quality and consumer participation in healthcare
- Primary and integrated care reform, including pharmacy reform
- Prevention and the social determinants of health
- Health financing and health system design
- National medicines policy, including quality use of medicines.

Multiple reports and the experiences of consumers and carers in the system over many decades highlight many problems and possible solutions to the challenges of mental health. This inquiry by the Productivity Commission, with its lens on both the social and economic benefits of improving mental health, comes closest to being the first ever whole-of-government, whole-of-system review conducted in recent history.

Mental ill-health affects all Australians and all aspects of our society in various ways. Rates of mental ill-health are climbing, as are costs to the health system and the economy more broadly. As the Treasurer noted in setting the terms of reference, in 2014-15 four million Australians reported having experienced a common mental health disorder. Mental health is a key driver of economic participation and productivity in Australia and hence has the potential to impact incomes, living standards, social engagement and connectedness. Improved population mental health could also help to reduce costs to the economy over the long term.

The mental health care system is siloed, where poorly integrated care, inconvenient and costly services and a lack patient-centred care is too often the norm. Misaligned and unmet needs are rife – for example consider the recent comments from the Austalian College of Emergency Medicine hospitals and emergency rooms are accepted to be an inappropriate setting for most

[1] Consumers Health Forum of Australia. 2018-2022 Strategic Plan: https://chf.org.au/2018-2022-strategic-plan, accessed 5 September 2018.

mental health interventionsyet at the same time the number of inpatient beds is too low to meet the needs of those in crisis or requiring longer term care But mental health care is about more than just the health system; it is everyone's responsibility. Mental health literacy, prevention programs, clinical care and social support should all be part of an integrated response delivered in coordinated ways across a wide spectrum of settings – schools, workplaces, primary care, community services and specialist services. This inquiry presents a chance to consider the mental health care system from this broad perspective.

Our approach to this submission

Our submission is structured around the questions contained in the Issues Paper published by the Productivity Commission in January 2019, *The Social and Economic Benefits of Improving Mental Health* (Issues Paper*)*. There are several questions posed in the Issues Paper under 17 themes. Not all are relevant to CHF and our constituency, others cover areas where we are not qualified to offer informed comment. We make some general comments on the overall scope of the inquiry, followed by specific comments and recommendations on the following on ten issues:

1. Assessment approach
2. Structural weaknesses in healthcare
3. Specific health concerns
4. Health workforce and informal carers
5. Social services
6. Social participation and inclusion
7. Education and training
8. Coordination and integration
9. Funding arrangements
10. Monitoring and reporting

We devote much of our commentary to the structural weaknesses in healthcare and to the major issues for our constituency: physical and mental health comorbidity and the management of multimorbidity. Both are becoming increasingly commonplace and are not well managed and, due to the complexity and mix of services required by consumers, their experience of the system is one of fragmented, disconnected services and care. Coordinated, multidisciplinary clinical and non-clinical interventions are required. Mental ill-health also results from, or is worsened by, biopsychosocial factors and social determinants. These matters are discussed in some detail in our submission and our main attention is given to the wider health system and how it works for Australians with mental ill-health or who are at risk of developing mental health problems, particularly those with co-occurring physical health problems and social care needs.

Our submission considers the lived experience of mental ill-health by incorporating preliminary results of the '*Survey of the Mental Health Lived Experience*'[2]. It is common for policy makers to focus too closely on a system and not the people in it, and it is CHF's hope that by including the voice of consumers in this submission that focus will be retained.

CHF designed the survey to inform our submission. It was available on the CHF website at https://chf.org.au/survey-mental-health-lived-experience, opened on 26 January 2019 and promoted on social media and throughout our membership and partner organisations.. The

[2] https://chf.org.au/survey-mental-health-lived-experience

survey will remain open to further inform CHF's work on this topic, at this stage until at least June 2019. Responses made after 14 March 2019 have not been considered as part of this submission. It is co-badged with the National Rural Health Alliance (NRHA) and results shared with consent.

Respondents were asked questions about their lived experience with mental ill-health directly, through caring for someone with mental ill-health, or experiencing its impacts through friends or family. Questions focussed on the experience of care from a system integration and patient centred perspective, and asked respondents about the supports, policies and attitudes of various sectors of society and how they could be improved. We have used illustrative free-text comments from responses gathered in pull-out boxes in this submission. Preliminary results and further information are available at Appendix A to this submission. A full analysis will be published in the coming months.

On the scope of the inquiry

The scope for the inquiry is well calibrated and is welcomed by CHF. The intention to "give greatest consideration to where there are the largest potential improvements in population mental health, participation and contribution over the long term" is appropriately broad. We concur with the Commission's initial assessment that a focus on people with mild or moderate mental illness, children and young people, disadvantaged groups and suicide prevention are the most appropriate points of focus. Important to the framing of the inquiry's recommendations is to recognise the right order of improved mental health, participation and contribution: while economic contribution is a vital goal, a mentally healthy population is more able to participate and contribute, therefore the primary goal must be on helping build a mentally healthy population.

Given it is often social determinants that are the factors that play a role in supporting people with mental ill-health to live productive and rewarding lives, CHF welcomes the fact that the inquiry will, among other things:

- examine how sectors beyond health can contribute to improving mental health and economic participation and productivity. Mental health policy, to date, has been constrained by being too limited to health policy.
- examine the effectiveness of programs and initiatives across all jurisdictions. It is important to consider the interplay across and between the various policy agendas and investments of the Commonwealth and States. To what extent is their duplication? To what extent is their gaps? How could the respective investments be best leveraged and coordinated?
- assess whether the current investment in mental health is delivering value for money. There is considerable expenditure on mental health services nationally however there is also considerable expert critique about whether some of this expenditure represents high value care. There may be cases where what is needed is not more money, but for that funding to be directed in different ways and targeted more effectively.

The final point in the terms of reference - to 'develop a framework to measure and report the outcomes of mental health policies and investment on participation, productivity and economic

growth over the long term'[3] - is among the most important outputs of this inquiry in terms of having a long-term impact on mental health from a policy perspective. A robust and understandable framework that can be used to discern positive and negative impacts of policies would enable vital work to be better prioritised across the economy and should, with the right refinements and further development, become an essential tool for each sector of society to use to develop, deliver and monitor their efforts to improve mental health.

Responses to specific areas of the issues paper

Assessment approach

CHF is satisfied that the proposed assessment approach will include a comprehensive and rigorous examination of the costs and consequences of mental ill-health, effectiveness, costs and gaps in current programs and supports and the likely effectiveness of alternative programs and supports to the extent there is data, evidence and expert opinion available to support this, some of which has been already referenced in the Issues Paper.

As the Issues Paper points out, many of the costs and impacts of mental ill-health are intangible and difficult to value in monetary terms. We would encourage the Commission to take an active approach to incorporating a systematic look at consumer and carer lived experience in its appraisal methodology. Only consumers and their carers/families see and experience the whole health system – and mental health services within that. Different clinicians and providers only interact with the system at various windows across the course of their patient's diagnosis, management, treatment and recovery.

There is sound evidence that consumer insights can shape better policy and services. These insights can help to frame problems, generate solutions, and suggest changes and improvements. They can also help counter the views of professional associations and providers which can, at times, represent a conflict of interest. It is possible to systematically capture and analyse consumer and carer narratives of their lived experience. One such tool for achieving this is *Real People, Real Data* (RPRD) developed by CHF with funding support from the Australian Government: https://chf.org.au/projects/real-people-real-data. RPRD has been used by the Department of Health, CHF members such as Dementia Australia, PHNs and agencies such as NPS MedicineWise to support policy, program and service development. CHF would welcome the opportunity to discuss how a series of consumer and carer lived experience stories could be analysed using RPRD as input to the Commission's inquiry.

Structural weaknesses in healthcare

CHF notes the Issues Paper indicates that the Commission will not generally be recommending changes in areas where reforms are currently in the early stages of implementation or where it is too early to evaluate outcomes achieved from reforms. CHF makes the following comments in relation to why we believe past reforms have failed or have had limited effectiveness, and

[3] https://www.pc.gov.au/inquiries/current/mental-health/terms-of-reference

structural weaknesses that are being overlooked. We recommend areas where structural changes would help overcome historical impediments to mental health reform.

Why have past reforms failed?

Mental health is a complex area of health policy but one that matters greatly to the Australian community. For policy makers, drawing a clear line around what is a mental health policy and financing issue and wider policy that otherwise supports a person to live a meaningful life with dignity and autonomy is difficult. More difficult still is judging the impact of wider policy settings on population mental health.

Expert commentators generally agree that the prevalence of mental ill-health in the community is not improving, rates of comorbidity are on the rise and we are not making sufficient inroads into getting suicide rates heading in the right direction. There are many reasons for this. CHF concurs with findings of the National Mental Health Commission's 2014 review that factors such as concentration of resources in costly acute and crisis care; fragmentation of services and poor coordination between them; services designed with a focus on the needs of providers rather than consumers and carers; and inequitable access to care especially for people in regional and remote areas and for disadvantaged groups are major impediments to reform.

CHF would add that other factors impeding the pace of reform also include:

- An over-reliance on the biomedical model of mental health care, as opposed to a biopsychosocial model that better includes the social and care structures a person exists in
- Blurred lines of responsibility and accountability between stakeholders in the system from governance, funding and service delivery perspectives that leaves some people to fall through the cracks and makes the system harder to navigate or coordinate
- A risk-adverse and/or rigid approach to implementation and failure to uncover and address 'teething' problems quickly and appropriately to ensure consumers don't fall through the cracks and the system continues to deliver safe and high-quality care as it transforms, and
- A lack of focus on outcomes and value, particularly at this early stage from the perspective of using evaluation, data gathering (including patient reported outcomes and experience data) and reporting to drive service improvement and system reform.

Overcoming the barriers

CHF acknowledges that there are several responses being made to the National Mental Health Commission's recommendations and as part of the implementation of the Fifth National Mental Health Plan, as well as action being taken by jurisdictions. It is not that action is non-existent, it is that it is largely ill-targeted using outmoded funding and care delivery models including the extent to which contemporary mental health care is harnessing the options now available with digital health. This is particularly in the primary and community care setting which is where most high prevalence, high burden comorbid mental ill-health is – or should be – managed and consumers rightfully expect that their needs should be met.

Consumers with multimorbidity is the norm and we know that people in these circumstances are not well served by accessing specialist mental health services alone. They need both a mix of clinical, treatment-focused interventions and services that will support their recovery many of which will be non-clinical and help avoid relapse. CHF believes that the fundamental problem is that mental health services need to be more integrated and that policy needs to be equally integrated to create a funding and implementation environment where comprehensive, multi-disciplinary and coordinated service delivery by a team of providers both within a service as well as across services settings is the outcome. The division of responsibility for policy and services across the Commonwealth, states and territories is a factor that continues to confound integration. Integration, for the most part, appears to happen by accident rather than design.

CHF suggests the following additional steps be taken at both the policy/system level and at the point of care to overcome the barriers which governments have faced in implementing reforms that meet this integration criteria.

At the policy and system level we need the following governance and policy shifts:

- *A COAG-led whole-of-government policy and implementation roadmap for mental health reform* that sets out a one, three and five-year agenda for action targeting areas where the return of investment is greatest and evidence strongest and that is clear about the obligations placed on various Commonwealth Departments and the jurisdictions

    - Inroads will continue to be stifled unless policy is more integrated and coordinated. Australians have a right to a universal mental health care system that integrates seamlessly with other parts of the system to give access to essential services in the right place, at the right time, and in the right way. Without a widespread, easily understood and shared vision for a person-centred mental health system with commensurate obligations for governments to act, making that right a reality may remain out of reach

    - Trust in government is low[4], as is the perception of government's ability to deliver effective reforms. CHF's recent (yet to be published) consumer sentiment survey found that cost and uncertainty are the top two health issues for consumers. People want to know that they can get the care they need when they need it and to be assured that governments have a plan to keep our health system sustainable. A COAG-led policy and implementation roadmap with co-design, high visibility and accountability could help instill community trust and provide the assurances people are seeking

    - The simpler and clearer the vision and principles of the mental health system can be, the better it will help health consumers and the health sector understand what world-class mental health care should look like and navigate its complexity as it reforms, and the faster the mental health system will be able to calibrate to meet it.

- A *regional infrastructure* to translate and implement national policy by serving stewardship, regional integrator, innovation accelerator and commissioning roles

[4] Edelman

- As the National Mental Health Commission (NMHC) and other inquiries and reviews have reported, there is international evidence that national health systems with strong primary care infrastructures have healthier populations, fewer health-related disparities and lower overall costs for health care than those countries that focus on specialist and acute care.

- We strongly endorse NMHC's view that the advent of PHNs provides the ideal opportunity to harness this infrastructure and better target mental health resources to meet population needs on a regional basis.

- PHNs should be given the authority and mandate to serve as stewards of integrated mental health, primary care and human services, and to commission services at scale. This will require them to have access to appropriate levels of flexible funds and to operate under highly transparent performance and accountability arrangements. These are currently not in place. CHF acknowledges that funding has been devolved to a limited number of PHNs to take early steps towards implementing localised stepped models of mental care. This is welcome thinking and should be accelerated, at the same time as ensuring PHNs have enough funding, commissioning maturity and skills to do so.

- Medicare should be strengthened through the development of regional budgets combining Commonwealth and State/Territory funding. These budgets would be flexibly administered by PHNs and LHNs, should prioritise integrated primary mental health care and have strong governance arrangements that mandate consumer and carer participation in decision-making.

- It is noteworthy that, as conveyed in the 2018 *Report of the PHN Advisory Panel on Mental Health* co-chaired by the NMHC and Mental Health Australia, there is variation in the maturity of PHNs as organisations and hence their commissioning, leadership and stewardship capabilities but nonetheless a longstanding commitment that their integral role in mental health should be strengthened, not diluted. The *Five-Year Horizon for PHNs* recommended by the Panel appears to offer much merit in terms of the actions that need to be taken to build PHN capability and further embed their roles if a desirable scale of transformation is to be reached particularly towards efficient, effective and person centred stepped care approaches.

- *New or evolved structures to monitor and independently report on progress and achievements* under the roadmap (also refer to our comments under ''Monitoring and reporting"). What consumers would like to see is change mapped out in *one plan and* monitored in *one report card*.

- The establishment of an *independent national mental health consumer and carer organisation*

    - Recent reports such as the National Mental Health Commission's *Sit Beside Me, Not Above Me* and the Productivity Commission's Issues Paper have put the spotlight on the deficits in national mental health policy and system governance. A missing

component in our national architecture is an independent, system-focused national mental health consumer and carer peak body. Such a body would ensure consumer and carer insights, aspirations for a better system and lived experience influence new policy and play a systemic role in shaping the future of health programs and services.

- CHF notes from Mental Health Australia's submission to the Commission that substantial consultation and a body of work to determine such an organisation's functions has already been undertaken.

- Consumer insights and involvement in shaping national policy and programs applies not only to specialised mental health services but also to the wider domain of health and social care services and the extent to which they cater for people with mental ill health. Just as mental health care must be well integrated into the system, so should the voice of mental health consumers and carers be more central in established consumer peak bodies at national and state levels, complementing other initiatives designed to support the participation of mental health consumers and carers in shaping policies and services and building their capacity to do so.

At the point of care we need:

- Systematically introduced stepped models of care
- Patient-centred health care homes that integrate primary health care services, self-management support and social prescribing
- Changes to outmoded, fee-for-service general practice funding arrangements to flexible payments that equip practice to take responsibility for managing and coordinating the care of patients with chronic conditions for a period.

We discuss the reform required for primary mental care delivery systems in more detail under 'Coordination and Integration' and 'Funding arrangements'.

What structural weaknesses in healthcare are being overlooked?

CHF believes there are three main philosophical and structural weaknesses that are presently overlooked. If addressed, these would make a difference to the way policy is shaped, and services delivered and accessed. The first is a policy ethos that puts consumer-centred care as the most important overriding consideration, the second is the benefits of investing in consumer leadership, and the third is the urgent need to address the out of pocket costs associated with mental health care access:

Real commitments to a consumer-centred system

The current system is so fragmented. When I was having a serious depressive episode (I have bipolar), I had to contact a long list of psychiatrists before I could find one. Luckily, I had the resources to pay as the only one that was available charged $600 for an initial consult.

It is so hard to even get to a GP sometimes when you have social anxiety, let alone persevere with medication side effects and costly appointments when things are no better.

The current mental health care system puts the needs of providers and funders in front of the needs of consumers, resulting in a mental health care system that is difficult to navigate, lacks integration and requires significant work by consumers and carers to coordinate their own care. The same is true of the wider health system.

CHF has been advocating for patient-centred care for many years, and recently released *'Shifting Gears'*, a White Paper that sets out the shifts that need to occur to create a health system that includes consumers at all levels: shifts that also apply to mental health. The health system must shift from:

• Illness to wellness	• Low to high value care
• Provider to people centric delivery	• National to local implementation
• Low to high performing person-centred organisations	• Siloed to collaborative integrated care and governance
• Information asymmetry to transparency	• paternalism to partnership[5]

The shifts described by CHF align well to the system vision articulated in *Contributing Lives, Thriving Communities - Report of the National Review of Mental Health Programmes and Services* which presented a picture of 'where we want to be' from a patient-centred mental health care perspective that identified the need for a system that includes:

- Widespread public knowledge and understanding
- People with lived experience, families and support people encounter a system that involves them in decisions, is easily navigable and provides continuity of care
- An outcomes-focused mental health system
- Access in the right place at the right time
- A mental health system that wraps around the person
- A system that responds to whole-of-life needs, and
- A proactive, strategically aligned system.

These shifts and a meaningful commitment to a consumer-centred system must be enshrined in policy.

[5] https://chf.org.au/sites/default/files/181125_shifting_gears_-_consumers_transforming_health.pdf

Investing in consumer leadership

In addition to the fundamental policy shifts that will drive more people-centred care delivery, the White Paper also identifies the various roles that consumer advocates can assume. Carers also have enormous expertise to bring to the table and can usefully fill many of the roles, as they understand the way the health system works, can help identify gaps and can speak about how the access to services really occurs.

However, it is vital to recognise that not all consumers and carers have the system literacy, confidence and skills needed to engage in the codesign of services and policies. Building consumer and carer capability and capacity to be partners in planning and decision-making is an obligation on government and health providers[6], not just so we can have a voice in policy planning and codesigning service delivery, but so we can be effective partners in our own health, support and treatment decisions[7]. There is particularly a need to not just better include those that can already speak up and contribute, but to also actively work to include those who can bring new perspectives to the table who would without effort remain marginalised, unheard, and underserved by the health care system.

To have a meaningful impact on broad health system change, the literature strongly emphasises the need to move beyond consumer participation to consumer leadership. A yet to be published literature review commissioned as part of the evaluation of CHF's *Collaborative Pairs Australia* demonstration project suggests that consumer leadership is an emerging field that includes driving a culture shift from typically seeing consumers as "users and choosers", to being valued as "makers and shapers" of health services.

If we are to advance the field of consumer leadership and harness the power of consumers in this space, we need to provide leadership opportunities for consumers to work collaboratively with health professionals and policy makers towards solving health system challenges. This requires investment. CHF's White Paper and our recently released *Making Health Better* priorities for the Federal Election [add link] recommends a number of consumer leadership initiatives that should be funded.

Out of pocket costs

I have had PTSD since 1977, and had my first case of shingles, so had to go weekly to GP for vitamin B injections for 2.5 years and have been on an antidepressant for at least 30 years. It has been very expensive. Thousands of dollars. I didn't have a healthcare card or any form of compensation.

It would have been useful if I did not have to pay $700 of my own money to get an autism diagnosis!

[6] CHF response to 5th mental health plan
[7] Shifting Gears page 12

The support from loved ones and the treatment and care from health professionals has allowed me to complete a university degree and maintain full time work. However, the financial cost of this treatment and care over the past 14 years has been huge and I've only been able to have this sort of treatment because my parents have helped me with the cost. I worry so much about people who aren't able to afford this treatment and care, and also people who don't have the emotional and practical support from family that I have been so incredibly lucky to have.

I can't estimate these costs. All I can say is that I do not earn enough money to access the services as often as ideally would have helped me, and often had to cancel appointments due to inability to pay and/or space them out more than needed.

Out of pocket costs are a significant and growing concern in the Australian health care system that diminish positive health outcomes and put at risk the fundamental principles of a universal health system. A universal health care system isn't universal if you can't afford to access it, and as noted by the Australian Council of Social Services (ACOSS) in their 2006 submission to the Senate Select Committee on Mental Health, 'a disproportionate number of people with mental illness live on low incomes, cannot afford co-payments and do not hold private health insurance.'[8] Delaying or avoiding treatment due to costs generally increases future health costs for the individual and particularly for State and Federal governments. Addressing this problem is not simple and requires a multi-faceted and iterative approach with buy-in from all levels.

There is a clear need for ongoing consideration to be given to what services attract expenditure by individuals but not government subsidy, and if found to be effective, they should be covered in the mental health care system. Health technology assessment mechanisms such as the MBS Review, the Pharmaceutical Benefits Advisory Committee (PBAC) and Medical Services Advisory Committee (MSAC) have key roles to play here, as do emerging approaches such as the certification of digital mental health services, social prescribing and ongoing reforms as to what private health insurance can and can't give rebates to. It is also important for consideration to be given in this inquiry to costs beyond direct financial payments by individuals, for example in terms of reduced superannuation and incomes for formal and informal carers, impacts on public services that deliver significant amounts on informal support to Australians accessing the social services system like libraries.[9]

There is also a clear need for much improved and apolitical measurement and reporting of out of pocket costs, as evidenced by the lack of clear data put forward when out of pocket costs are raised in the media. A recent example is with the issue of out of pocket costs for radiology and diagnostic imaging and Labor's multi-billion-dollar election promise to cover costs of those

8 https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Former_Committees/mentalhealth/report/c12

9 https://www.alia.org.au/sites/default/files/Australian%20Libraries%20-%20the%20digital%20economy_website.pdf

scans for consumers diagnosed with cancer[10]. Progress is hampered without a shared understanding of what consumers are paying for and when. Recommendations on this issue are made in the "Monitoring and Reporting" section of this submission.

In January 2019 CHF and the University of Melbourne released a position statement on areas of improvement with regard to specialist fees and performance transparency[11]. It notes the importance of practical attention on areas of policy around bundled payments, increased fee transparency, a focus on quality, strengthening the role of private health insurance and private hospitals, improving financial consent, and establishing effective complaints mechanisms. CHF also broadly supports the recommendations made in Russell and Doggett's recent report, 'A road map for tackling out of pocket health care costs'[12].

Specific health concerns

This section of the Issues Paper poses a number of questions relating to mental illness prevention, early intervention to reduce the severity of mental illness, effective forms of mental health promotion, changes required to better address comorbidities among people with a mental illness and overseas practices.

Comorbidity and multimorbidity

I have many physical conditions that need treatments as well as my mental health. I always have to have a long appointment when I visit a GP. The GP does bulk bill, but you have to have the money in your account and pay upfront for the $100 or so consult, then you can get the gap back on your card. I'm constantly having to choose between whether to get see my doctor because of my physical problems or mental health problems. It's a constant juggling act and because of this and because of the costs of GP visits, neither my physical nor mental health is getting the care it needs. I find this extremely upsetting and stressful.

Some people are supportive, others not. Some people understand one area/issue, although often no or little knowledge/understanding in other areas. Often physical symptoms have been dismissed as mental. A huge mouth pain dismissed by many until a dentist referred me to an oral specialist - saw them and the next day a pre-mouth cancer cut out. I was told that if I'd gone public would've died waiting.

As discussed earlier managing multimorbidity has emerged as a priority area of reform, particularly regarding the impact it has on out-of-pocket costs and the inefficient experience

[10] https://www.catherineking.com.au/2019/04/05/labors-medicare-cancer-plan/
[11] https://chf.org.au/sites/default/files/190129_position_statement_-_specialist_fees_and_performance_transparency_roundtable.pdf
[12] https://apo.org.au/sites/default/files/resource-files/2019/02/apo-nid219221-1331226.pdf

presented by a fragmented health system[13]. The *Equally Well Consensus Statement* – to which CHF is a signatory - is a vitally important rights focussed signpost, agreement and call to action for governments to ensure the rights of Australians with equity in access to care and physical health outcomes for people who live with mental illness. It asserts that:

"Mental health and wellbeing are a basic human right often denied to many in our community. People living with mental illness have poorer physical health, yet they receive less and lower quality health care than the rest of the population – and die younger."[14]

The *Consensus Statement* makes a clear case for government action on six key areas, and commits signatories to making the physical health of people living with mental illness a priority at all levels through six key principles:

1. a holistic, person centred approach to physical and mental health and wellbeing
2. effective promotion, prevention and early intervention
3. equity of access to all services
4. improved quality of health care
5. care coordination and regional integration across health, mental health and other services and sectors which enable a contributing life
6. the monitoring of progress towards improved physical health and wellbeing

Addressing multimorbidity also requires structural changes and 21st century models of care – particularly in the primary care setting - that implement the shift towards a patient-centred health care system and take advantage of digital transformation. These opportunities and CHF's recommendations are discussed elsewhere in this submission.

Medicines policy

Anyone with a chronic mental health condition that needs to take medication to keep them stable should be able to access a health care card to reduce the financial impact of medications on them and their families. That might reduce non-compliance in taking medications.

Specialists tend to discount your contribution to your own care. It is ridiculous to expect someone to follow your prescriptions blindly when you cannot get to see them more often than every 3 months. Side effects can be intolerable in a very short time-frame

Medication safety and quality use is an increasing focus of government health policy, with recent examples including funding for real-time prescription monitoring[15] and using My Health

[13] Sum, G., Hone, T., Atun, R., Millett, C., Suhrcke, M., Mahal, A., … Lee, J. T. (2018). *Multimorbidity and out-of-pocket expenditure on medicines: A systematic review*. BMJ Global Health, 3(1), 1–12. https://doi.org/10.1136/bmjgh-2017-000505

[14] https://www.equallywell.org.au/wp-content/uploads/2018/12/Equally-Well-National-Consensus-Booklet-47537.pdf

[15] RTPM ref

Record to avoid adverse drug interactions[16],[17]. This is a specific health concern that is not canvassed in the Issues Paper, but an area CHF believes warrants some attention in the Commission's Review.

A recent study prepared for the Australian Commission for Safety and Quality in Healthcare (ACSQHC) led by Professor Libby Roughead found that there is significant variation in medication safety practices among mental health services including:

- wide variation in the quality of prescribing pro re nata (prn or 'as needed') medications, evaluation of their effects and documentation of the reason for, or effect of, prn medications,
- a poorly met desire among consumers and carers for more personalised information on their medicines, including better engagement in shared decision-making around treatment options, and
- frequently inadequate monitoring of the effects and side effects of medication and confusion among clinicians on whose responsibility it is to do so.[18]

CHF broadly supports the core recommendation of the report to better adapt the medication safety practices that are more common in general health settings to mental health settings, and the strategies proposed for doing so.

CHF proposes that a key next step from Government should be increased funding for engaging stakeholders in applying the Quality Use of Medicines framework[19] to mental health settings.

Consumers have also raised the issue of confusion and bureaucratic barriers to getting some medications when in different states and expressed surprise at times at how little ePrescriptions are available.

Early Intervention

As the National Mental Health Commission found, we have a mental health system that responds too late. Early intervention approaches seek to minimise treatment delays which in turn maximise the chance of recovery. It is often taken to apply only to early treatment of children and young people, but the principles and practices can apply to adults for those mental illnesses that can emerge later in life.

Early intervention is, or at least should be, a fundamental principle in health care as we try to deal with problems as they begin to stop them escalating and becoming more serious. It is the reason why there are continued calls for more investment in primary health care. One of the most noticeable gaps in our service system for people with mental illness is early intervention but this has gradually been shifting over the last two decades. There is now a growing body of

[16] ADHA media release on medication safety in Tville floods
[17] ADHA on testbed for medication safety
[18] https://www.safetyandquality.gov.au/wp-content/uploads/2017/06/Medication-Safety-in-Mental-Health-final-report-2017.pdf
[19] http://www.health.gov.au/internet/main/publishing.nsf/Content/National+Medicines+Policy-2

evidence to show early intervention works and this, in turn, has led to some service reforms, particularly in the field of youth mental health.

It is clear that early intervention to deal with issues as soon as they arise helps reduce the severity of some mental illness and can reduce the impact it has on young people's capacity to contribute and participate in society. More than three quarters of mental health issues develop before a person turns 25 and yet the services were not designed to assist young people to seek help. In 2006 headspace, which uses an early intervention model, was established to work with young people to help them get the assistance they needed and manage their mental health.

The 2019 Federal Budget announcement of a trial of adult walk-in mental health centres is an attempt to improve early intervention by extending the headspace model to adults. CHF supports this concept in-principle provided it is implemented in a way that sees it well integrated into existing care delivery systems. More broadly, CHF strongly endorses the recommendations of the *Contributing Lives, Thriving Communities* Report of the National Review of Mental Health Programmes and Services by the National Mental Health Commission that the "cost curve" needs to be shifted to more efficient and effective 'upstream' services and supports that are preventative and early intervention in nature, away from high cost specialised services.

We would echo the views of other expert commentators that we have not got the investment balance right between these kinds of services as well as recovery-based community support, stable housing and participation in employment, education and training, and specialist services. It is well documented that countries with the highest performing health systems are those that have well-resourced and functioning primary health care systems. CHF contends that the same principle applies to systems of mental health care delivery and we would encourage the Commission to closely examine reform opportunities in this area in terms of what interventions and care settings deliver high value mental health care.

Health workforce and informal carers

There is considerable scope for development and innovation in the mental health workforce. Consumers should be able to access care in the right place and at the right time for them, however long waiting times between initial contact and appointment and structures that tie specialists to particular settings or scopes of practice below their skills often stand in the way.

Interprofessional education and interprofessional collaborative practice

GPs often describe feeling ill-equipped to deal with people with complex mental health issues and of not feeling well placed to provide the assistance people need. That a single primary health care clinician such as a GP should be expected to manage in these circumstances reflects past models of healthcare and is not reflective of best practice, contemporary mental health care that a developed country such as Australia should be able to efficiently and effectively deliver using all the appropriate levers at its disposal such as available and emergent workforce, scope for financing reform, enhancements to the way clinicians are educated and trained and digital health solutions.

First and foremost, we need a workforce that is trained in consumer-centred care and in working in multi-disciplinary team-based care. This is not always the case in the current health care system, let alone the broader mental health care system. There have been some promising forays into this arena such as the work of the Mental Health Professional Network, although it is not clear the extent to which this has been evaluated for impact on practice and teamworking, nor whether it has evolved to be more inclusive of consumers as educators.

Workforce attitudes and perceptions

Before contemplating improved consumer-centred care and interprofessional collaborative practice, a fundamental starting point is workforce attitudes and perceptions. In 2016 CHF undertook a national survey of health workforce professional organisations to ascertain attitudes towards and understanding of patients as partners in care; policies and procedures of the organisations regarding patients as partners in care; and wider views on health system and workforce reforms.[20]

The results showed respondent organisations had a strong understanding of the principles behind patient-centred care, showing that they clearly had an appreciation of the rationale behind patient-centred care. However, the translation of patient-centred care into both organisational policies and practices promoted among their membership is mixed to and an area in need of development. This is also supported by the mixed views we found regarding how patient-centred the entry level curricula is. The heartening finding was that respondents recognised that rather than fundamental attitudes being problematic, the issue preventing patient-centred care being more routine and embedded was structural impediments that prevent this being the case. The area of strongest agreement was that the current fee-for-service funding arrangements so predominant in our system needs to be changed to allow organisation's members to work in a patient centred way in team configurations.

> *Too many to mention!! Eye rolling, forgetting my name during treatment, making negative assumptions about my gender and ethnic background, speaking down at me, referring to me as Just The Mother, rushing into prescribed medication rather than willing to listen, using terms such as 'terrible ' and 'too hard basket' and most of all... telling me I can never expect to lead a fulfilled life. Terrible.*
>
> *We sought public hospital support, were told they would come after 5 days they didn't assess, and my son attempted suicide. Team was very aggressive and combative.*
>
> *They fobbed off my concerns. They rushed. They were uncomfortable.*

The curriculum for all health professionals should also include mental health first aid training along with a discussion of mental ill-health, especially around early identification of issues and

[20] Consumers Health Forum of Australia (2016) The Patient Centred Health Workforce. Canberra, Australia

how to work with patients to address these. Whilst it may be there in most curricula many health professionals are not comfortable with discussing it and appear to prefer to avoid it.

Expanding roles and emergent roles

Consumers consistently talk of waiting times to get assistance through current services. They also describe not knowing where to go to get help and finding the service system difficult to navigate. For example, one consumer told us through the survey of the mental health lived experience that:

> *Early on in the process, I was left to coordinate supports through trial and error.*
>
> *There is no coordination of all the services. There are so many separate groups and most people have no idea where to go to for help and often manage alone. It is a minefield to navigate.*

This experience is common place and has implications for models of care as well as where Australia could either develop new workforce or extend existing roles. A key area for workforce development and innovation would be to introduce service navigators or ''link'' workers on a more systematic scale as the UK has done under its recently announced plan to deliver better self-management support, *Universal Personalised Care: Implementing the Comprehensive Model*. Such a role should, in theory, steer consumers more efficiently and effectively to the right mix of services and result in more efficient and targeted service access and utilisation.

In addition, we need to make better use of the skills that each potential mental health professional brings to the team- based care approach. For example, pharmacists are medicines experts and they should be working as part of the team, working in a collaborative way with other health professionals in both primary health care and hospital-based care. There is scope to increase the role of hospital-based pharmacists for people with mental illness. having them participate in inpatient and community outreach care. CHF has long called for more pharmacist involvement in general practice and they could be particularly useful in working with GPs managing people with chronic mental illness. There has been some movement in this regard with funding for pharmacists in general practice being available through the expanded Workforce Incentive Program as announced in the 2018 Federal Budget and some PHNs also funding these roles.

Other groups, including nurses and psychologists, should be encouraged to work up to the full scope of practice. We note that nurse practitioner-mental health is a developing area within the Australian system. Nurse practitioners are trained to work autonomously and collaboratively and can form help to link services together for consumers. There are currently funding and other barriers, including a reluctance from some health professionals to recognise the skills these groups can bring to the table. If we are going to have patient centred-care then we need to make sure that the structures, including appropriate funding models, are in place. Consumers do not want health professionals competing or "owning" consumers, they want them to collaborate.

A further workforce consideration is the place of roles introduced in other health systems such as the low-intensity psychological coach workforce under the UK's IAPT initiative. This emergent role is nested into a service model described as "New Access" that fits well with a stepped care approach and we understand is being steadily rolled out via PHNs with funding from the Commonwealth, followed by a demonstration program funded by beyondblue and the Movember Foundation. However, CHF understands that New Access coaches are not available nationally. We would like to see accelerated rollout of such a model particularly in light of recent commentary of the expensive nature of the Better Access Program and the NMHC's recommendations about the need to shift the cost curve towards more services of this nature.

Peer support workers

In our survey of the mental health lived experience, many respondents raised the benefits of peer support and the value of growing the peer support workforce and integrating them more commonly into existing care models.

Positive peer influence - people who have experienced mental illness and found good ways to live with it - sharing their story

I want more education around domestic violence and supportive joined up services- use of peer workers who understand and can guide.

Mental health care is holistic. It cannot be assisted in isolation. Peer workers are a great asset to understand the situation and navigate services. I wish I had one as my journey may have been quite different.

Given the value mental health consumers place on peer workers, CHF would support any measures that promote a wider, more systemic uptake of the work progressing through the National Mental health Commission on the peer workforce.

Social services

We confine our comments on this aspect of the Issues Paper to matters pertaining to how non-clinical mental health support services could be better coordinated with clinical mental health services. We believe social prescribing offers the Australian system considerable promise and its implementation should be the subject of a nationally evaluated trial in the first instance. Social prescribing is a way to help consumers link into source of support in their community to help improve their health and wellbeing. It recognises that people's health is determined by a range of social, economic and environmental factors and that changing these are as important as meeting clinical needs.

Social prescriptions are designed to encourages individuals to take greater control of their own health, to self-care more effectively and provides supports to do this. Social prescribing probably works best for people with mild or long-term mental health problems, vulnerable

groups, people who are socially isolated, and those who frequently attend either primary or secondary health care.

Social prescribing is being increasingly promoted and implemented in the UK's NHS. In Australia, some GPs and mental health services actively refer to local support groups and other community services although probably do not term it social prescribing. There have also been forays into what could be described as more structured attempt to introduce social prescribing through programs such as the Personal Helpers and Mentors and Return to Day to Day Living initiatives prior to the introduction of the NDIS, and how subsumed into some limited funding to PHNs to commission targeted non-clinical support services.

Our survey indicated a desire by consumers to access social and community supports with 38 respondents saying their health professional directed them towards social and community supports, and 25 saying that this wasn't their experience. Consumers also noted many times in the survey the impact on their family of mental ill-health, the challenges faced in helping loved ones get access to appropriate care, and the positive impact that help from loved ones has on coordination of care and healing over time. This suggests that there is room to take a closer look at health professionals' perceptions of social prescribing, the extent to which they currently practice it and the barriers they experience in practicing it and the value it would bring to their practice. This could take the form of a survey of GPs and other health care professionals.

In the UK social prescribing is probably a more commonly understood term than here in Australia and, while the models differ in terms of target groups and activities, they usually include a link worker or navigator to help people access local supports. One of the strengths of these approaches is that it builds on existing networks, so people can be linked into local supports, rather than trying to create new structures that may not suit local needs.

The UK Kings Fund claims "there is emerging evidence that social prescribing can lead to a range of positive health and well-being outcomes.[21]" but warns that robust and systematic evidence on the effectiveness is limited in part because the models are disparate, and the studies are small scale. They also rely heavily on self-reporting of outcomes which in itself is not necessarily a negative as we are looking for more consumer input through patient recorded experience and outcome measures. There needs to be a systematic way to collect such information.

Some of the issues which needs to be addressed in rolling out a social prescribing initiative would be around the placement of link workers; availability and accessibility of self-care and self-management services; funding for referral, mechanisms for self-referral and IT support. What is needed is a number of small-scale trials, in different communities using different mechanisms to work out which models work and, more important, what are the success factors and what are the barriers. Given that its strength is that it builds on existing networks the trials should allow for a range of models that are designed to suit local communities, considering existing services, characteristics of the community. These could be led through a selected

[21] The Kings Fund 2017 What is social prescribing viewed at https://www.kingsfund.org.uk/publications/social-prescribing

number of PHN vanguards, preferably those already someway down the track of implementing stepped care approaches to ensure integration.

Social participation and inclusion

Social participation and a sense of inclusion are protective factors that guard against a person developing a mental health problem in the first place and are also factors that play a key role in recovery. While clinical care may well be effective, its effect can be diluted substantially if the settings in which an individual lives, works and socialises is not mental health promoting.

The medical system has been effective..... but society has handicapped me!!

The impact of mental illness is severe in our society. Everyone who suffers regardless of diagnosis, experiences massive social and career withdrawal. They are made to feel like they are no longer part of society. This is far from the truth! They are worth just much if not more because of lived experience. They are more valuable than gold.

Whole of society and social determinants approaches

It is not just the responsibility of the mental health care system to provide help. Every person, every organisation or institution, and every sector of the economy has a level of obligation to help people access the right care when they need it, lessen the impacts of mental ill-health on their lives when they do, and make sure they stay connected to our community as they recover.

Extending the core principle of the Australian health system (universal access to safe and quality health care) to become a responsibility of not just the health system but society in general is a useful lens through which to consider what reforms should and shouldn't be on the table. In our response to the Fifth Mental Health Plan, we noted that it recognises the importance of a whole of society approach, but that it lacks a pathway to implementation[22]. This inquiry presents an opportunity to consider the pathway to implementation and develop a Framework that can aid society in travelling that path. A COAG-led whole-of-government policy and implementation roadmap for mental health reform as we recommended under the 'Structural Weaknesses' section of this submission could remedy this.

Mental health is not just the responsibility of the health system – each sector of society and each member of society has a responsibility to grow their mental health literacy to better acknowledge and understand the impact of mental ill-health, where they can play a supportive role and where they have obligations to act appropriately and in the interests of people with mental health ill-health or risk factors. This is particularly the case in key settings such as schools and workplaces. While there have been efforts such as the Mentally Healthy Workplaces program, CHF recommends that the Productivity Commission consider how to

[22] CHF response to 5th Mental Health Plan

incentivise the development of mental health action plans by each sector of our economy that are effective, well-informed, and ideally cost-positive for that sector.

Taking a social determinants of health approach is also critical. Access to housing, fair and equitable justice systems, barriers to accessing services by Culturally and Linguistically Diverse (CALD) Australians or the Aboriginal and Torres Strait Islander (ATSI) community, and fundamental questions of the issues caused by inequality must be considered to create a system that truly takes in the social needs of people. If there was one single measure that should be taken to promote social and economic participation to improve mental health it would be to raise the Newstart rate.

Stigma and discrimination

In the survey of the mental health lived experience consumers told us that stigma and discrimination are often experienced and have significant impacts on their ability to engage fully with society.

> *"As a carer, there is always stigma by association. We often hide behind the white picket fence, not telling our friends and employers, for fear of retribution or exclusion."*
>
> *"It has had a huge impact on the type of work I can do in that it has to be no stress, good company to work for and very flexible work place to allow me to take care of my needs first. My employer does not know I have a mental health disorder as I am sure that my decision making would be judged."*
>
> *"Mental health care is available through our health system, but people with mental ill health are often reluctant to access it. Mental wellbeing needs to become more commonly discussed and sought, so that people with mental ill health feel more comfortable going to seek treatments before crisis point"*

Responses to the survey raised consistently and clearly the issue of real and perceived stigma and discrimination. Many called for more to be done to educate the community, workplaces, government and financial institutions about the realities of living with mental ill-health, understanding trauma, and how to accommodate sensitivity for people's mental health into 'business as usual'.

> *It has had a huge impact on the type of work I can do in that it has to be no stress, good company to work for and very flexible work place to allow me to take care of my needs first. My employer does not know I have a mental health disorder as I am sure that my decision making would be judged.*

CHF agrees with these calls for more education to reduce stigma and discrimination, however, do not feel that education will be enough. It is assumed by many that changes to community attitudes will lead to institutional level improvements, however institutions almost by definition

resist change and perpetuate current structures. Fundamental improvements to the issues of stigma and discrimination may not be possible until there are effective and widely understood protections in place in workplaces and other institutions that can then flow on into the community more broadly.

Institutional workplace discrimination in relation to health conditions are a particular concern for some Australians. This was seen, in part, in the public's recent response to My Health Record that led to legislative changes to explicitly prohibit data held in My Health Record being used for employment related purposes[23]. It is also evident from some responses to our survey that poorly implemented workplace policies and practices can impede efficient and effective return to work and working conditions for people with mental ill-health. CHF would encourage the Productivity Commission to consider these issues in its inquiry.

"The organisation that I used to work for has policies in place to help but sadly it was all lips service. HR department did little to reach out and provide support. Managers were inadequately trained to handle staff with mental health issues. In the end, you were left feeling even more vulnerable as people were staying away from you.

Member of the organisation's senior leadership team sent an email to HR department stating "I don't know how to handle this situation" when his direct staff informed him about his struggle with mental health. The staff was on personal leave for over 2 months with doctor certificate stating his conditions. During his time away from work, not one person from his organisation contacted him to see how he was doing. Not a get-well card. Not an offer to provide support in any shape for form. Yet this organisation proudly promoting wellness programs."

Work cover treats you like a criminal and that you are "faking it" and ignore doctor reports. Their own psychiatrist said I had a relapse. Who in their right mind would fake a mental illness.

Education and training

One of the key issues that needs to be addressed is increasing the recognition of mental ill-health and equipping people to deal appropriately with people exhibiting symptoms so that the episode does not escalate. As we have encouraged people to undertake first aid courses and learn resuscitation techniques, so we need to educate them to deal with mental ill-health, especially when people might be in crisis. The aim of mental first aid, as with physical first aid, is to assist and support until appropriate professional help is received.

We have had mental first aid courses for some time in Australia as it has been recognised as an important part of the service continuum. There is clearly a need for people who are in roles

[23] My Health Records Amendment (Strengthening Privacy) Bill 2018 https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/Bills_Search_Results/Result?bId=r6169 TK

more likely to come across people with mental ill-health such as all health professionals and hospital staff, paramedics, police officers, customer service officer in services like Centrelink, banks and post office, to be trained.

However, everyone can benefit, not just in terms of providing support, but in the way it would help to improve mental health literacy, helping people to be aware of their own mental health and having greater understanding and empathy for those who have ill-health.

In its Call to Action in 2018[24] the CHF Youth Health Forum identified the need for more consistency in the approach to mental health training for all first responders. Whilst they acknowledged that it was supposed to happen there were many examples of where the training was inadequate, and the first responders did not feel confident of their ability to manage a situation. Whilst this is predominantly a State and Territory issue the Commonwealth government could take leadership role by taking it to COAG Health Ministers for discussion and action.

The CHF Youth Health Forum also identified the need for more resources for improving education and training for teachers, support staff and students about mental health. There needs to be an emphasis on mental health literacy and open discussion about mental health issues in early secondary school curriculum. This would improve understanding and assist with destigmatising mental ill-health, encourage young people to seek help and for school staff to be able to offer appropriate support and referral to other services.

A copy of the CHF Youth Health Forum's submission to the Inquiry has been submitted to the Productivity Commission.

Coordination and integration

The siloed nature of the mental health care sector and the need to address it has been an issue recognised by successive Australian governments since at least the release of the 1992 National Mental Health Policy. Fragmentation and poorly coordinated care increase costs, duplicates services, makes the system harder to navigate and reduces the rate of positive outcomes for consumers, as well as frustrates the health professionals trying to provide effective care.

Consumers often feel left to 'fend for themselves' when trying to coordinate their care and rely on family and their own research to attempt to make the best decisions for themselves. Support is often found from GPs, other health professionals and advocates in the community sector among others, however this support can be fragmented, conflicting and ad-hoc.

[24] CHF Youth Health Forum 2018
https://chf.org.au/sites/default/files/chf_yhfcall_to_action_final_002.pdf

In the public hospital system, the person I was caring for was told what to do by a different health professional each visit. This mostly involved a new medicine prescription for a medicine with strong side effects and very little discussion.

I have no support with coordination, I direct my own care

Early on in the process, I was left to coordinate supports through trial and error

Support is almost hidden, it is difficult to find support groups in remote and rural settings for both the carer and the person with the mental illness

There are several recommendations made throughout this submission that we believe these will assist with improved coordination and integration of the mental health system and wider health system to the benefit of mental health consumers and carers. We have not repeated them here. They range from how policy can be more effectively "joined-up", to a systemic role for PHNs as system integrators and stewards, to new models of primary mental health care.

Stepped care approach

CHF strongly endorses the implementation of a stepped care approach in Australia as well as the NMHC's recommendation that the fundamental elements of the stepped care approach lies in prioritising delivery of care through general practice and the primary health care sector. PHNs have a fundamental role to play in introducing a stepped care approach and this has been recognised in the Government's response to the NMHC's 2014 report which committed to strengthening and extending the role of PHNs, then newly established, to provide a regionally driven approach to mental health services and which foreshadowed the PHNs as commissioners and system integrators of mental health care, particularly through the adoption of a person centred, stepped care approach.

Coordination and integration are not just an issue within the health sector, but also of how the health sector integrates and coordinates with the wider network of services and supports, particularly in the disability space. Recent reports like that of the Joint Standing Committee on the National Disability Insurance Scheme[25] highlight that this scheme has significant psychosocial gaps and a need for immediate resourcing and upskilling, and improved reporting. Issues have also been raised of the impact that strict in/out requirements for NDIS support and/or access to other government funded services or payments have, particularly in terms of people not knowing which door to knock on to get support or finding that their particular challenge or set of challenges does not attract direct support and they've fallen through the cracks of the bureaucratic system. Disability support is but one domain of social care support available to people with mental ill-health. Our report, *Snakes and Ladders: The Journey to*

[25] General issues around the implementation and performance of the NDIS - https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/General_NDIS

Primary Care Integration, which reflects the views of a panel of expert consumers, clinicians and researchers, outlines a key role for PHNs in health and social care integration] more broadly and we would encourage the Commission to consider its recommendations and how they could be integrated into current efforts by PHNs to support stepped care approaches.

Shared decision making

In a patient-centred system, consumers must be involved in all levels of the system. Patients as partners in care is now a compulsory National Standard. Shared decision making is a fundamental characteristic of best practice service delivery and is a fail-safe way, if not the most important measure, in assuring that a patient's care is well coordinated because it ensures that a care plan is centred on what matters to them. However, consumers have told us through the Survey of the mental health lived experience that they were not as involved in the decision-making process as they wanted to be. They also raised that consideration also needs to be given to the barriers in place to better involving family and informal carers in the shared decision-making process. Consumers shared with us experiences about privacy and confidentiality rules cutting them out of the process, the difficulty in helping people whose mental ill-health or attitudes towards help-seeking were diminishing their health and mental health outcomes, and the damage to trust and adherence that being treated as care recipients, rather than as partners, led to.

> *A lot of the time I felt like I had lost any sort of control in making decisions, the "goal posts" felt like they kept moving and sometimes it seemed like the "team" of professionals didn't know what each other were doing or trying to achieve. I lost confidence and trust.*
>
> *When my partner was Form 1 I had no say in his treatment, the health nurses and doctors told our family to stop ringing and ask how he was.*
>
> *I have a positive and respectful approach, so I'm treated with respect. I've been lucky, I guess.*

The survey's preliminary results also showed that the majority of respondents did not often feel confident they knew what the next step in their treatment was, roughly half recalled discussing what their goals or hopes were with their health professionals, and the majority were not given a physical or digital copy of their treatment plan.

Realising the benefits of including consumers as partners in their care requires that more work be done on making the changes needed to improve patient activation and better include consumers as partners in their care and the care of their loved ones. Given that discussion about and recording of goals for treatment is already required as part of creating GP Mental Health Treatment plans under the Better Access scheme[26], interventions to better incentivise ensuring consumers get their own copy of that plan appear easily achievable in the short term.

[26] http://www.health.gov.au/internet/main/publishing.nsf/Content/pacd-gp-mental-health-care-pdf-qa

In the longer term, broadening similar incentives and requirements to consultations for other types of care could lead to significantly improved outcomes for consumers, as could working towards flexible but standardised formats of treatment plans improve health literacy, system navigation, and inform better service design through more effective data collection.

Primary care reform and patient-centred health care homes

Mental ill-health is typically chronic and ongoing requiring care coordination over time. The hallmarks of patient-centred health care homes are best most recently described in *Better Outcomes for People with Chronic and Complex Conditions*, the report of the 2015 Primary Health Care Advisory Group (PHCAG) and include coordinated, comprehensive and personalised care; support to activate and empower patients to play a role in shared decision making, voluntary enrolment, funding reform, and enhanced use of practice level data for service improvement. The rapid introduction of such models of care in Australian general practice supported by appropriate funding and inclusions such as self-care programs, social prescribing, link workers and shared decision making would be of benefit to mental health consumers, particularly those with comorbidities. Self-help options to help people, their families and communities to support themselves and each other and improve ease of navigation for stepping through the mental health system should also be built in.

The Better Access program has been a key piece of the mental health service delivery environment for several years now. It has experienced high utilisation and exponential expenditure, far exceeding budget estimates. In conjunction with other primary care reforms recommended by us, CHF also supports calls from experts that the Better Access program which provides for GP mental health care plans and referral for up to 10 Medicare subsidised visits with mental health allied health providers such as psychologists and appropriately qualified social workers should be redeveloped to maximise its benefit. Writing recently in the Medical Journal of Australia Rosenberg and Hickie outline flaws with the program and suggest that it is expensive and not as targeted as it could be.

Digital transformation

Effective digital transformation has a significant role to play in the reform of the mental health care system. Fundamentally, all involved in digital transformation must understand that it is about a change to 'business as usual', and that just bolting on digital touchpoints to current processes will lead to, at best, doing what is currently done but a bit faster. Team based health care requires technical improvements, like secure messaging and interoperability but, even more so, it requires changes to clinical workflows and funding arrangements as well as cultural change to equip health care providers with the confidence and skills to embrace digital enablement into their modes of practice.

Enhancing coordination and integration in the health care system requires that other reforms and transformations that are underway recognise the role they also play in this area of reform too. For example, there has been little work done publicly on how the Consumer Data Right will be brought to the health sector, yet it should have a significant impact on coordination and integration among various supports and services. Electronic health records and clinical information systems are across Australia are receiving billions of dollars of funding, yet are not

greatly used in mental health, and face similar interoperability issues in communicating information outside the health care system as they do communicate inside it. All major reforms should be considering how they can take a coordinated approach to solving these challenges, and the impact that each has on other reforms.

A barrier to better alignment of digital transformation processes between sectors, services that better 'wrap around' a person, and bureaucratic processes that better take an individual' circumstances into account are often legislative ones that prevent information from being shared between sectors or programs, or even within the same agency to transfer a person from one type of support to another.

Our other thoughts on how better coordination and integration of care delivery systems could be achieved are discussed under other relevant sections in this submission such as 'Structural Weaknesses', 'Funding Arrangements' and 'Specific Health Concerns'.

Funding arrangements

It is well known that the way health care services are funded drives clinical behaviour. CHF has long argued that financing reform – particularly in the primary health care sector – is long overdue. Several of our major reports and thought leadership pieces – most recently our *Making Health Better* report articulating our priorities for the Federal election, have recommended a modernisation of Medicare involving the introduction of patient and family centred health care homes that would feature voluntary enrolment, blended and bundled payments for general practices to configure teams of health care professionals to provide coordinated, convenient, multidisciplinary care, including the scope to more actively use non face to face modes for care delivery such as skype, facetime and email. The same reform is required in primary mental health care delivery.

Shift from fee-for-service

Central to implementing patient-centred care and models such as the one described above is a shift from the fee-for-service to an alternative team-based care model that is outcomes focussed and value based. This holds true in the shift to a patient centred mental health care sector as well. We note that work is underway in this area in some respects, with for example the NDIA plan to start trialling alternatives to a fee-for-service delivery model to address thin markets in rural and remote areas by the end of 2019[27], however what is most vital is that a coordinated approach is taken such that mental health care reforms are considered and trialled alongside initiatives to bring that approach to the health care sector. CHF recommends that the Government take steps to ensure that mental health care is considered integral to shifts towards patient and family centred health care homes, particularly when those models are being trialled and evaluated.

Competition and commissioning

[27] Senate Joint Standing Committee on the National Disability Insurance Scheme -Progress Report

Competition between service providers to deliver public services is often put forward as a method to improve access and quality, however as noted in the Productivity Commission's report into Human Services competition and contestability are only a means to the end of improving service provision[28]. The fundamental measure must always be whether overall improvement to the lives of consumers occurs.

Recognising that the market that does exists is, 'disciplined not by consumers/buyers substituting one supplier for another, but by government regulation and monitoring of supplier behaviour'[29] is necessary when considering any service delivery program. Not doing so leads to fragmentation, loss of knowledge among key providers, thin markets for particular challenges or in certain geographic areas and is not going to lead to the universal system of coordinated and integrated mental health care that Australian's have a right to.

CHF broadly supports the explanations and recommendations in the ACOSS Briefing Note – 'Commissioning and Getting Better Outcomes'[30].

Effective place-based commissioning should be considered in this inquiry. Issues stemming from the federalisation of our health system are well noted but far from overcome. CHF supports the recommendations of the NMHC's *Contributing Lives* report to shift funding to rebalance the system and support the Government response to fund locally planned and commissioned mental health services through Primary Health Networks[31] (PHNs) as an appropriate response to the benefits of subsidiarity. CHF also broadly supports the AHHA's call for moving further towards a nationally unified and regionally controlled patient-centred health system[32]. PHNs are still a new reform, and formal evaluation of their effectiveness is likely premature. However, there are clear areas for improvement that could be considered at this stage, such as:

- Improved coordination mechanisms and tools between PHNs, such as:
    - digital marketplaces for procurement
    - shared resourcing and contracting arrangements, including pooled funding for regions
    - Improved methods of analysing and disseminating 'what works'
- Better coordinated reporting on performance, and implementing performance indicators that support better coordination between PHNs
- Consideration of tying funding to performance
- Ensuring integration of actions with the Federal Department of Social Services and state level equivalents.

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[28] https://www.pc.gov.au/inquiries/completed/human-services/reforms/report/human-services-reforms-overview.pdf
[29] https://www.acoss.org.au/wp-content/uploads/2018/09/ACOSS-Choice-Final-Report.pdf
[30] https://www.acoss.org.au/wp-content/uploads/2018/10/ACOSS-Briefing-note_Commissioning-and-Getting-Better-Outcomes.pdf
[31] http://www.mentalhealthcommission.gov.au/media-centre/news/giant-steps-towards-building-the-mental-wealth-of-the-nation.aspx
[32] AHHA blueprint

Monitoring and reporting

To be effective, it is imperative that outcome measures and indicators that have "gravitated to the most easily measured and least controversial indicators"[33] instead provide a clear picture upon which coherent ongoing reform can be built. Underpinning all monitoring and reporting is the capture, aggregation and analysis of data about consumers' health, and service utilisation.

Social licence

In making recommendations about monitoring and reporting, the Commission should keep in mind social licence. In CHF and NPS MedicineWise's 2018 report, '*Engaging consumers in their health data journey*', a key finding was that, "low levels of trust were displayed in all the types of organisations investigated in both the interviews and surveys (government, private and research).'[34] Measures must be taken to preserve and improve the trust that consumers place in government to manage their data safely, and use it well to enhance the public good. This is best done by proactively building the social licence for programs that rely on government use of citizen's data consistently and clearly over time. Given the stigma often associated with mental health diagnoses and the sensitivity some consumers have around disclosure, there is a heightened need to pay attention to social licence.

Beyond simply informing consumers, consideration must also be given to implementing dynamic consent, and to whether certain projects should not go ahead until dynamic consent becomes possible. CHF research done with NPS MedicineWise found strong consumer support for having the ability to give consent on a project by project basis[35]. The potential benefits of dynamic consent are not just around building trust, it also provides the potential to better communicate back to participants the impact that sharing their data has had and how it has been used in the public interest such as improving services.

CHF has, in previous reports, recommended that government consider the benefits to increased public trust by implementing dynamic consent principles for projects that use data held by government. We have also suggested public education about data and its use to retain the social licence required to hold and use that data. Resources such as 'Understanding Patient Data[36]' by the United Kingdom's NHS are an example of what helps consumers understand how their data is used and build trust that it is being used well.[37]

What outcomes should be measured, and by who?

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[33] Jackie Crowe referencing Rosenberg https://chf.org.au/blog/reform-revolution-and-disruption-mental-health-care-consumers-perspective#refList15
[34] https://chf.org.au/sites/default/files/engaging_consumers_health_data_report_updated.pdf
[35] https://chf.org.au/sites/default/files/engaging_consumers_health_data_report_updated.pdf
[36] http://understandingpatientdata.org.uk/
[37] https://chf.org.au/sites/default/files/submission_-_chf_response_to_issues_paper_on_data_sharing_and_release_legislation.pdf

There is significant focus in the health sector on measuring service delivery and activity, but less on outcomes and experience. Too often, organisations settle for proxies when instead a patient-centred system should be focussed on what consumers want and get from the health system. Too often, data is collected to meet government reporting requirements rather than to drive reform[38] or improve safety and quality. To quote former National Mental Health Commissioner Jackie Crowe:

"Measuring service activity provides little information about the consumer and family outcomes that are being achieved and the cost of that care. Advocates (especially consumers) have long emphasised and demanded a move from system inputs and outputs, and process measurement, to quality outcome measurements. To their disappointment, 'quality outcome measurement' has gravitated to the most easily measured and least controversial indicators"[39]

CHF notes that the Productivity Commission has in many respects led the way in better including true outcome measures, with a recent review for example noting that there are now well-established ways of assessing patients' experiences through Patient Reported Experience and Outcome Measures (PREMs and PROMs).'[40] Both long and short term measures are needed, and they must be supported by effective and quick feedback loops of service quality improvement.

An area of improvement for the Productivity Commission to consider is in some of the consumer-focussed areas of the yearly Report on Government Services (ROGs). From a mental health consumer perspective, a number of critical areas in ROGS do not yet have data[41],. Despite these issues featuring strongly in consumer surveys as important and being essential for judging system integration or patient-centricity, there is no data or agreed measures in this year's report on:

- Affordability of mental health care
- Consumer and carer experiences of services
- Stigma and discrimination experienced by people living with mental health problems
- Mental health service use estimates.

Addressing these gaps should be considered. With regard to patient reported outcome and experience measures, the work of the NSW Agency of Clinical Innovation in reports like, 'Patient Experience and Consumer Engagement: A Framework for Action' and Safer Care Victoria's approaches may be instructive to the Productivity Commission in this area.

Increased role and powers for National Mental Health Commission (NMHC)

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[38] Rosenberg, S. P., Hickie, I. B., McGorry, P. D., Salvador-Carulla, L., Burns, J., Christensen, H., … Sinclair, S. (2015). *Using accountability for mental health to drive reform summary*. Medical Journal of Australia, 203(8), 328–330. https://doi.org/10.5694/mja15.00447

[39] Jackie Crowe referencing Rosenberg https://chf.org.au/blog/reform-revolution-and-disruption-mental-health-care-consumers-perspective#refList15

[40] https://www.pc.gov.au/inquiries/completed/productivity-review/report/2-healthier-australians#c26

[41] https://www.pc.gov.au/research/ongoing/report-on-government-services/2019/health/mental-health-management/rogs-2019-parte-chapter13.pdf

As a general principle, CHF advocates for maximum transparency in measuring and tracking the performance of the health system overall. The NMHC has a core role to play in independently reporting on the state of the mental health care system however reviews have found they do not have the resources necessary to entirely fulfil their role[42], and they can face jurisdictional challenges in getting access to the data needed to adequately report on the indicators they have charge of. Further revision and clarification of the powers, support from State Governments, and independence of the NMHC and its Commissioners is required to ensure the shift towards the patient-centred outcome and value measures needed to evaluate the mental health care system as reforms is needed.

A 2017 review by Deloitte had four key recommendations[43];

- Lift the capacity and capability of the NMHC
- Clarify the role and governance of the NMHC through an update to the Executive Order and regular correspondence via a Ministerial Charter
- Clarify the NMHC's internal governance and operations, and
- Take steps to strengthen the NMHC's influence and impact.

Some reform in these areas is underway, with for example the recent Federal Budget increasing their staff allocation, however CHF is concerned that the NMHC lacks the powers required to effectively compel Federal and State Departments to share the information they need to appropriately report on their indicators, and whether the NMHC has sufficient backing from COAG.

The Australian Healthcare and Hospitals Association (AHHA) has called for the development of an authority that would be the single source of truth for health data collection in its Blueprint[44] that would rationalise the work currently undertake by organisations such as the ABS, AIHW, and ACSQHC. Whether this vision comes to fruition of not, there is a clear need to reduce duplication of effort and wherever possible combine resources and reporting to amplify reach and preserve resources. Where there is close alignment in goals, remits and reporting processes underway currently, effort should be made by government agencies to integrate efforts and work alongside one another to optimise the extent to which our system overall has an effective means of monitoring and report outcomes, including in mental health.

Annual parliamentary report

Effective mental health reform in CHF's view requires the development of a 'shared truth' of the reality of the mental health care system and how it is experienced by consumers and carers. Much as the Closing the Gap report has done for ensuring that a clear picture of the ongoing reforms towards achieving equality in health and life expectancy for Aboriginal and Torres Strait Islander people has done for that area of reform, a similar report on the experience of living with

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42 https://www.health.gov.au/internet/main/publishing.nsf/content/D015B02A481D8BC8CA2581D000014AC7/$File/Strengthening%20the%20National%20Mental%20Health%20Commission.pdf

43 ibid

44 AHHA Blueprint

mental ill-health that is not swayed by political or bureaucratic concerns of the moment could be a vital touchstone on the road to effective reform in mental health.

There are already significant data collection processes underway that could be used to inform such a report to Parliament, that with some coordination and appropriate stewardship could see this yearly report implemented in a short time frame. CHF believes this report is both achievable and vital and should attract bipartisan support. This report is the fundamental touchstone needed to ensure understanding, focus and will are coordinated to give Australia the mental health care system it has a right to be supported by. CHF suggests the report should be accessible and meaningful for consumers; take whole of government perspective; use data that is already collected by government or improves the data collection underway to give a clear picture of the consumer experience and is stewarded by an independent organisation such as the NMHC.

Appendix A

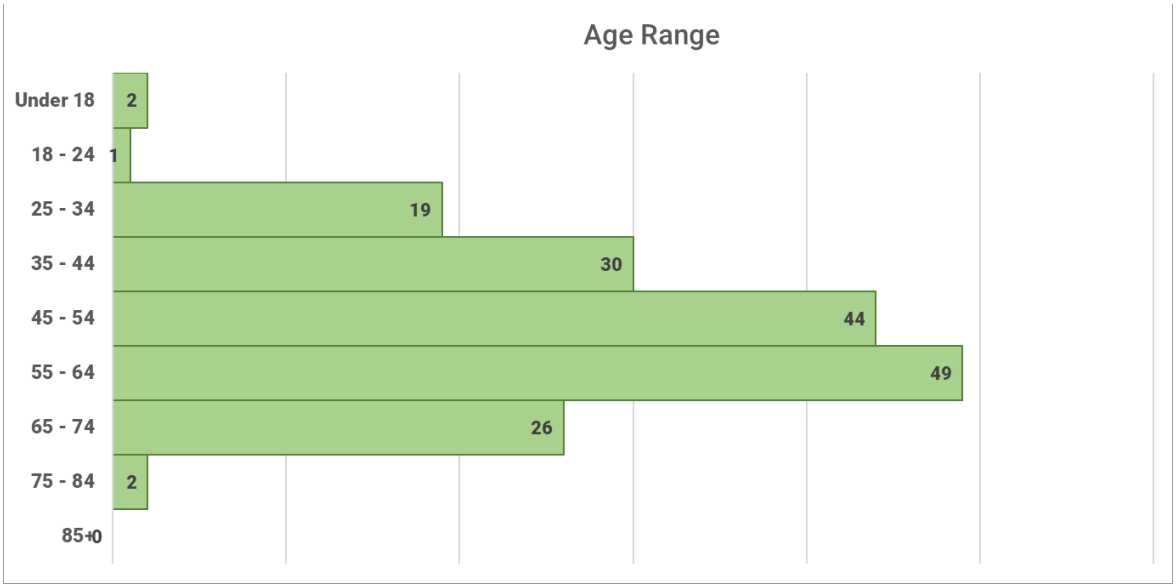
Topline results of the 'Survey of the mental health lived experience'

The survey available at https://chf.org.au/survey-mental-health-lived-experience was opened on 26 January 2019, and responses made after 14 March 2019 have not been considered as part of this submission. The survey will remain open to further inform CHF's work on this topic, at this stage until at least June 2019. It is co-badged with the National Rural Health Alliance (NRHA) and results shared with consent.

Respondents were asked a number of questions on their lived experience with mental ill-health directly, through caring for someone with mental ill-health, or experiencing its impacts through friends or family. Questions focussed on the experience of care from a system integration and patient centred perspective, and asked respondents about the supports, policies and attitudes of various sectors of society and how they could be improved.

178 responses were received in this timeframe. Please note that very few questions were required, so the sample size is different for most of the findings and graphs below. Respondents were found from among CHF's member organisations, consumer representatives, broader email lists and via social media. Other organisations, such as the NRHA and a number of PHNs also shared links to the survey through their networks. No paid advertising has been conducted. Therefore, the sample of respondents skews towards those who already have some level of understanding of and engagement with the health system, and the results included here should not be taken as necessarily indicative of broad public sentiment.

Demographics of Respondents

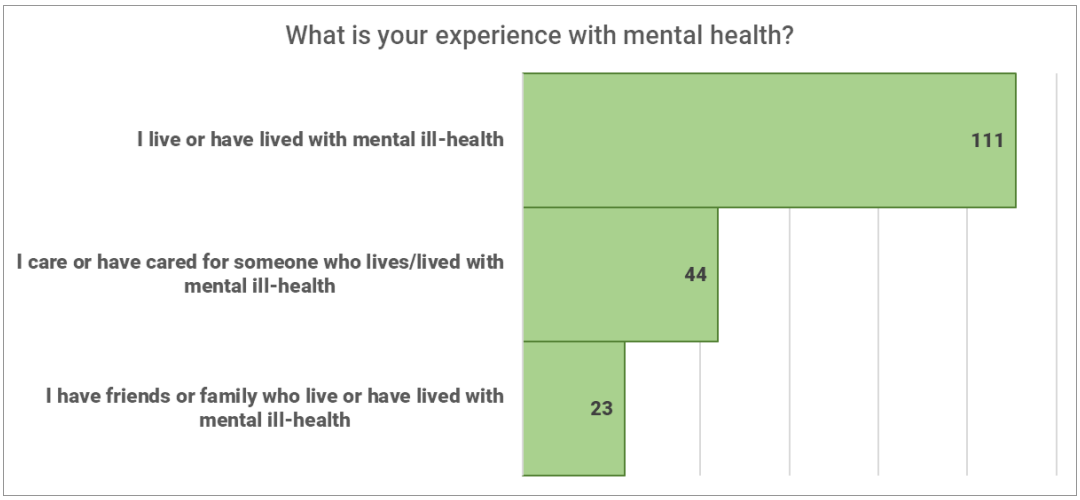


Respondents were also asked to provide their postcode to allow segmentation by rurality using the Modified Monash Index however as no segmentation based on those responses has occurred at this preliminary stage they will be left for future reports.

Your Experience

What is your experience with mental health?

The majority of respondents indicated that they lived or have lived with mental ill-health. Answering this question is mandatory as it provides essential context through which to understand the answers given by respondents in the rest of the survey.

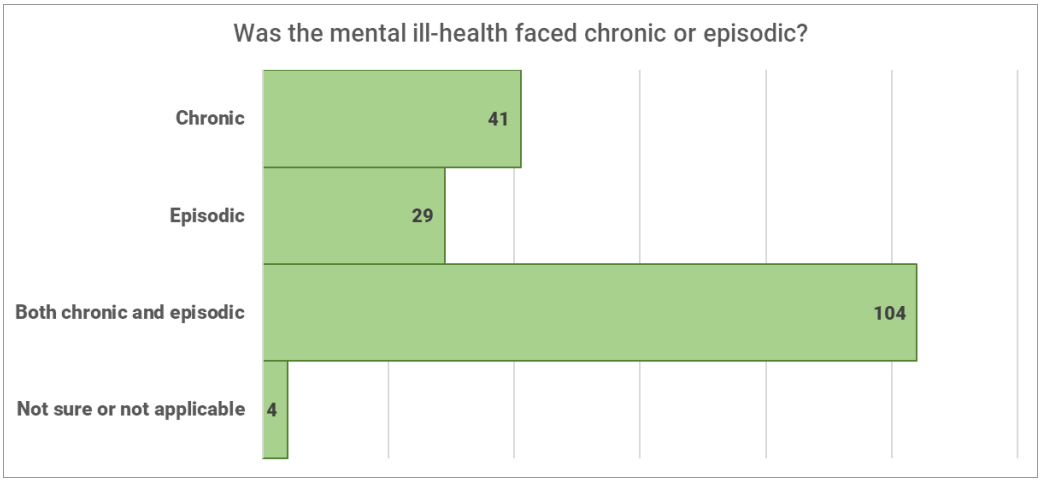


Analysis on the questions below asked in this section will be provided in the final report:

- Were you or the person living with mental ill-health under 18 when help was first sought?
- Approximately how many years ago was help first sought to manage mental health?
- Is mental ill-health still an issue today?
- Approximately how many years ago did the mental health problem stop being managed?

Was the mental ill-health faced chronic or episodic?

The majority of respondents indicated that the mental ill-health faced was both chronic and episodic. The definition given in the survey of chronic and episodic was; "*Chronic = long lasting, had an impact all the time, Episodic = periods of wellness with episodes of debilitation, had an impact some of the time*".



Is there anything else you'd like to add about the chronic or episodic nature of the mental ill-health?

Full analysis of the free-text answers given in response to this question is under completion. 67 responses were given, and examples that demonstrate the issues raised are included below.

It's unpredictable and there is a lot of uncertainty as to when it will get bad again

Only just been diagnosed with bipolar 2 after 43 years of battle

Undiagnosed for many years or incorrectly diagnosed until only a couple of years ago

The onset of episodes is not predictable - it can happen just when you think everything is going okay.

Approaching my 60th birthday, I am only now starting to realise what happened in my early childhood that has impacted my mental health and who I am, basically all of my life.

Living in regional rural Queensland it can become isolating as chronic is ongoing. It never stops.

The issue was initially an eating disorder but has evolved into episodic anxiety

Always present, although has fluctuated in severity over the years. I felt as though I was diagnosed with anxiety and depression when I believe that I was just battling with a serious medical incident which took some time to adjust to

Ongoing Chronic depression with episodic bouts of severe depression that leave me incapacitated

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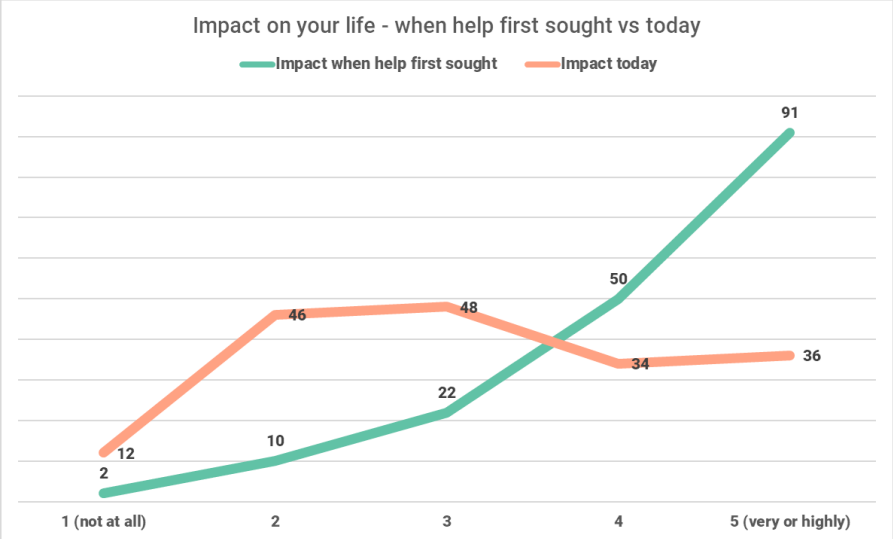
Severity and Skills

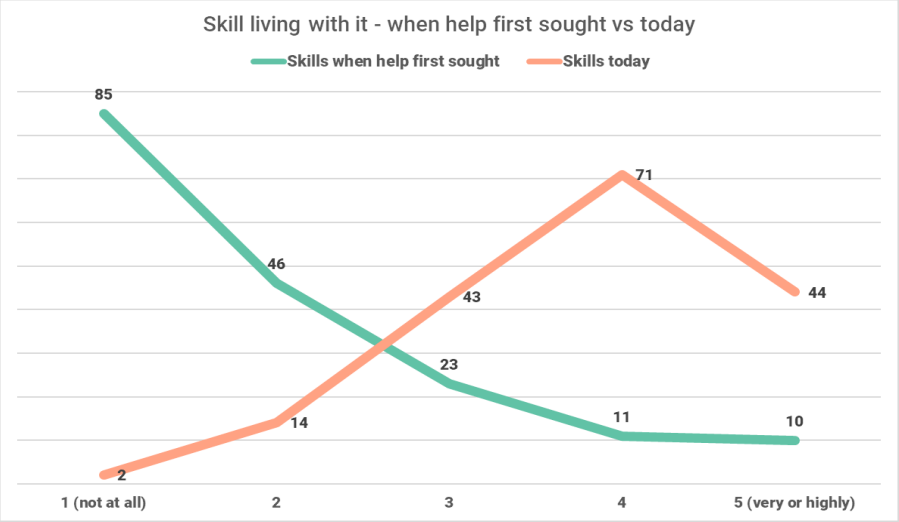
Respondents were asked to rate from 1 (not at all or none) to 5 (very or highly) the severity of impact of mental health on their quality of life when help was first sought, and today. They were also asked how skilled they were in living with mental ill-health when help was first sought, and today. The explanatory information provided to respondents was;

"When thinking about mental health, it can be useful to understand both how much more difficult mental ill-health makes your life (severity) and how good you are at dealing with the difficulties that come from it (skills). This is called the 'dual continuum' model.

We want to understand your perspective on the severity of the impact mental ill-health has had on your life, and how skilled you think you were in managing it to reduce that impact."



These results indicate that respondents generally found the impact quite severe when they first sought help, and that over time had found ways to reduce the severity of impact.

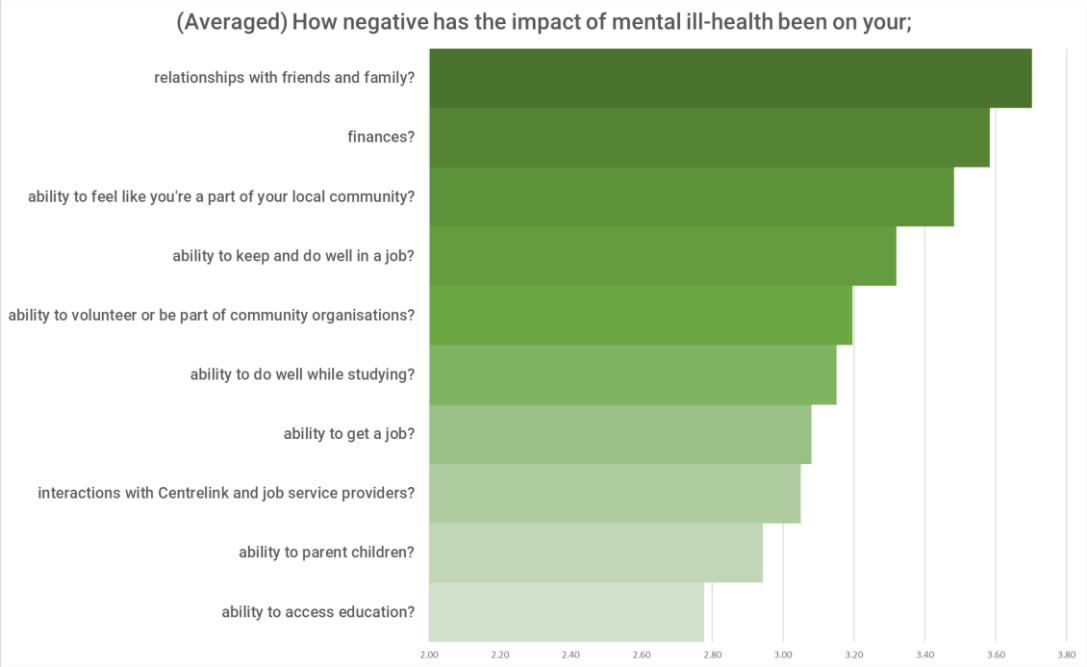


These results indicate that most respondents thought they had little skill managing the impact of mental ill-health when they first sought help, but over time significantly increased their skills in living with it.

Impact

How negative has the impact of mental ill-health been on aspects of your life?

Respondents were asked to rate from 1 to 5 (where 1 = no impact, 3 = some impact, 5 = severe impact) 'How negative has the impact of mental ill-health been on your ability to get a job, ability to parent children and so on *(respondents asked to demonstrate impact of mental health on a series of areas of life that could have been impacted)*. Taking an average of the responses given demonstrates that respondents believed mental ill-health had the greatest impact on relationships with friends and family



Respondents were also asked to expand on their answers should they see fit and examples of the potentially instructive answers are provided below . A comprehensive analysis of the responses will be conducted as part of the final survey report.

When I couldn't access services quickly my mental health got worse and it took me longer to recover

I spent years projecting an image of coping and would use my ability to work and study well as evidence that nothing was wrong.

It has affected my relationship with my father who has lived in denial of his mental health condition. My mother's health mental and physical health has been severely impacted by no support from the mental health system!

If we had support and education as a carer at the beginning of our journey, life would have been a bit easier.

I have chosen to work in the community sector as it is more flexible and able to accommodate for my needs. But it has been to a financial cost to me, and that has also impacted the amount of help I can pay for.

Job service providers are intolerable. I feel that the stress they caused me contributed to my stroke last year.

Employment agency and Centrelink requirements continue to be the number one reason in forcing me to stop work/study/volunteer work, make it impossible to retain etc due to Mutual Obligation requirements and dramatically contribute to deterioration of Mental well-being. Also, lack of access to suitable services and locating information/services during school hours.

I cannot deal with most things while in a depressive state. Getting lower costing power - you can't negotiate that when you're sick!! You can't arrange a payment plan for utilities or rent when you are sick. And you can't explain to people why last week you were keen to see them, but a week later, you've gone from manic to the depressive and can't meet.

As a carer, there is always stigma by association. We often hide behind the white picket fence, not telling our friends and employers, for fear of retribution or exclusion

What other long term impacts to your life do you think mental ill-health has contributed to?

Respondents indicated that mental ill-health had significant long-term impacts on their lives. Further analysis will be provided in the final report. Some of the potentially instructive responses are below.

It affects all of my life

Loss of self-esteem and confidence, feelings of being branded as "other".

Continual stress, if I am out in the community I am always scanning the area around me and get very jittery. I am always in flight or fight mode.

Big impact on my own mental health due to limited time and flexibility to plan my time, but mainly due to constant negative talk from my now adult son who cannot work, study or see friends. Very dependent on me to talk and assist with any appointments and other needs.

Ability to sleep soundly, ability to concentrate and complete tasks.

Ability to effectively run a household

Ability to live independently. Ability to travel independently

Ability to participate in physical activities to maintain mental and physical wellbeing

Ability to shop (agoraphobia). Diagnosis of my Severe Depression enabled me to receive assistance and medication has allowed me to live a fuller life without retreating behind a persona of "being perfect" in everything I do within the workplace and community and has allowed me to acknowledge I can just be "me as I am" take it or leave it.

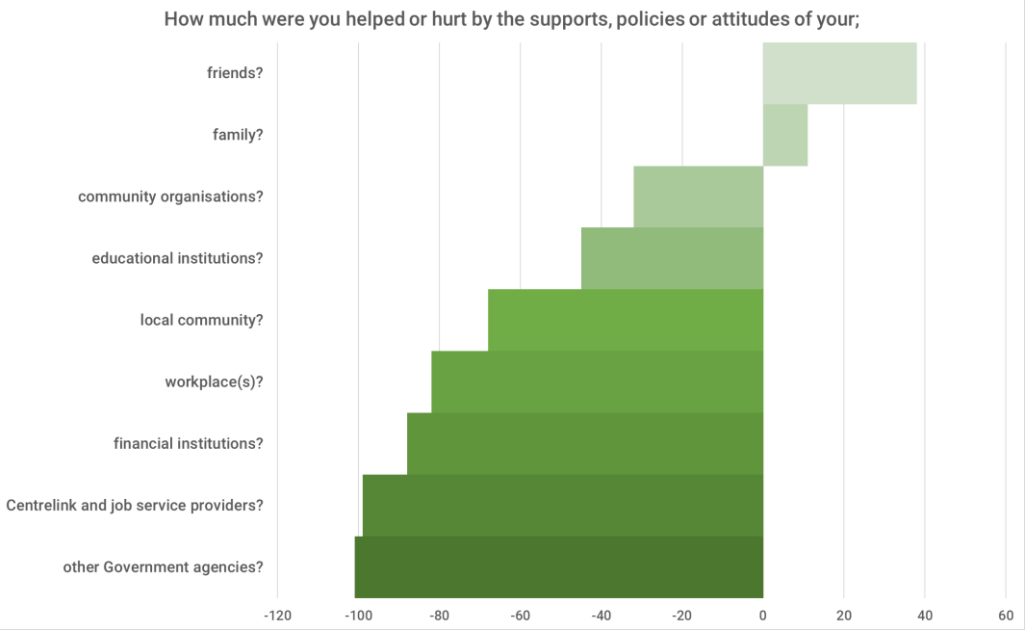
I have made poor choices or avoided making choices and have therefore not realised my full potential in life. I am highly skilled, qualified and driven yet cannot find work in my area due to discrimination and the fall out of being outspoken. My future is bleak.

Financially. Just outside health benefit card limit, wife has no income. Medications and gap payments make life difficult as like many in this situation whom I know, we have a number of other chronic conditions.

I chose not to have children because of possible harmful effects on the children and myself, in some ways I regret this, but mostly glad. Because of poor decision-making, substance abuse and mental illness, I've acquired a criminal record that nearly could've been avoided if the general community was more aware of effects of dual diagnosis

How much were you helped or hurt by the supports, policies or attitudes of your friends and family?

Respondents were asked to rate from -2 to 2 (where -2 = significantly hurt, 0 = neutral, 2 = significantly helped). The results also indicate that friends and family are a positive help. Taken with the above results of mental ill-health having the most significant impacts on family and friend relationships that they have a core role to play in the mental health care system and should be supported as such. The below figure sums the responses given by all respondents to provide a comparison of the impacts of different areas.

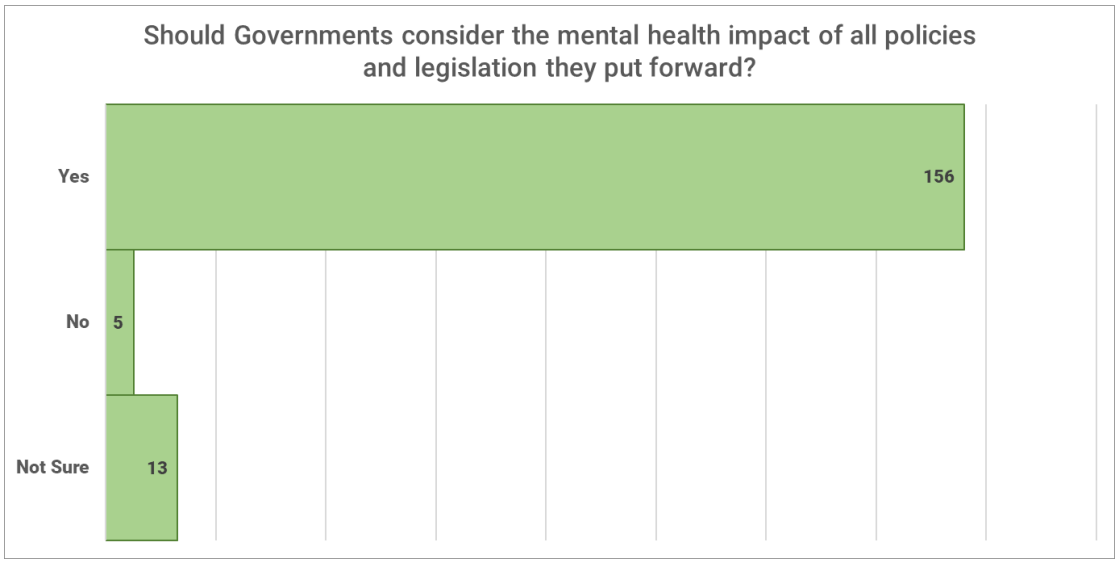


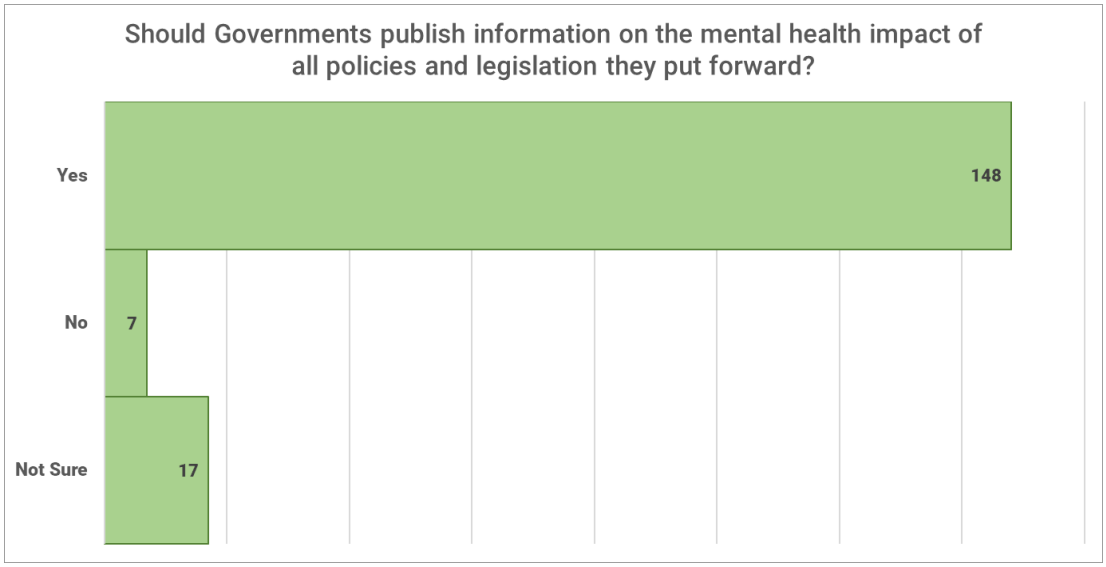
That the supports policies and attitudes of the major institutions, i.e. finance and government, were found to be the most negative, this suggests that improvements in those areas may also provide the most significant benefits.

Analysis on the alternatives proposed in this section has formed part of this submission, with further detail to be published in the final report for this survey.

Government Policies

Within the survey of mental health lived experience, we asked consumers if Governments should consider the mental health impact of all policies they put forward, and whether they should publish information on the impact. The response was strong, with 89.6% of respondents who answered the question indicating 'yes', and 86% indicating 'yes the impact should be published'.

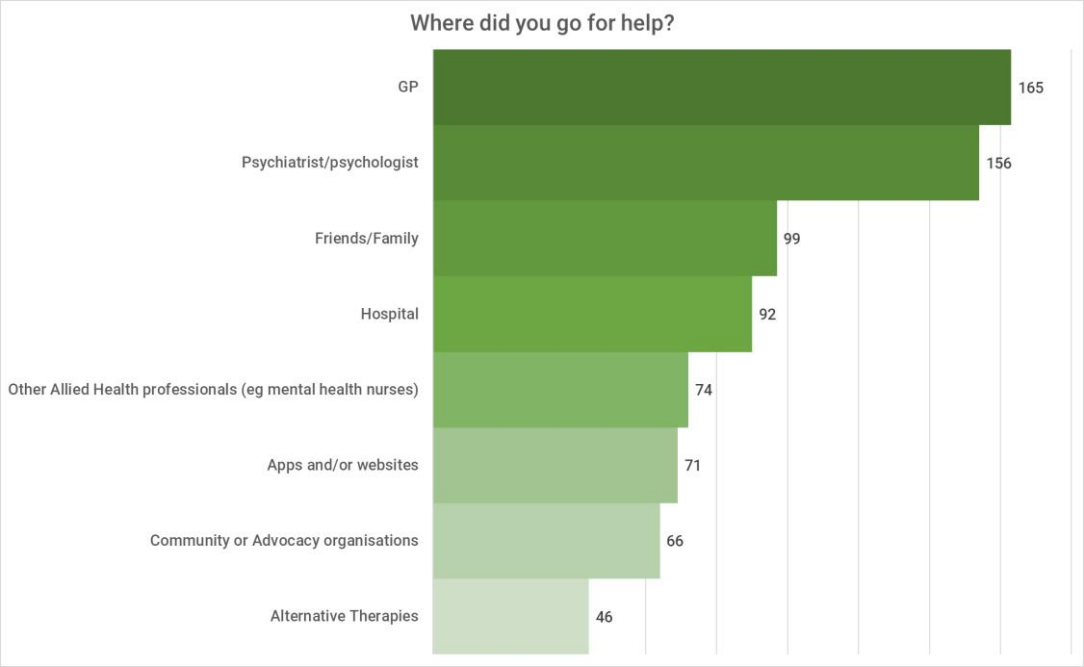




Respondents were also asked in this section whether they had ever asked a government agency or financial institution to alter a decision or deadline due to mental ill-health, how difficult they found it, and what could have been done to make it easier. Analysis on the responses to these questions will be provided within the final report.

Getting help

Where did you go for help?



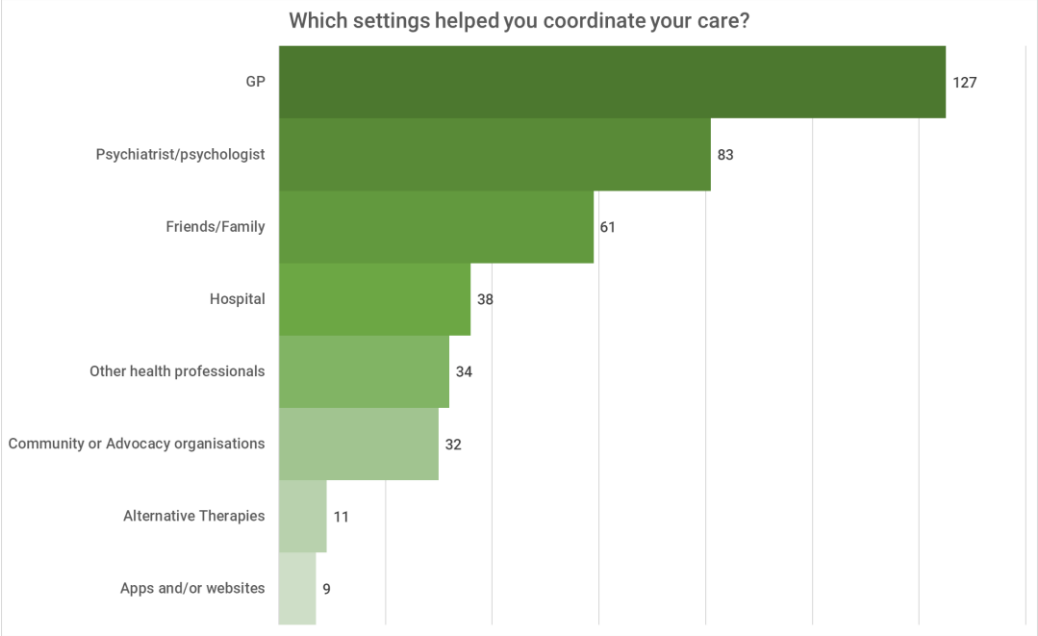
Respondents were asked to indicate which settings, 'in or near the health system you looked for help with managing mental health.'. Further analysis on this question, the time it took to receive help, and how much they spend trying to improve their mental health in each area will be conducted for the final report.

Empowerment

Consumers have told us through the Survey of the Mental Health Lived Experience that they were not as involved in the decision-making process as they wanted to be. They also suggested that consideration also needs to be given to the barriers in place to better involving family and informal carers in the shared decision-making process. Consumers shared with us experiences about privacy and confidentiality rules cutting them out of the process, the difficulty in helping people whose mental ill-health or attitudes towards help-seeking were diminishing their health and mental health outcomes, and the damage to trust and adherence that being treated as care recipients, rather than as partners, led to.

Which settings helped you coordinate your care?

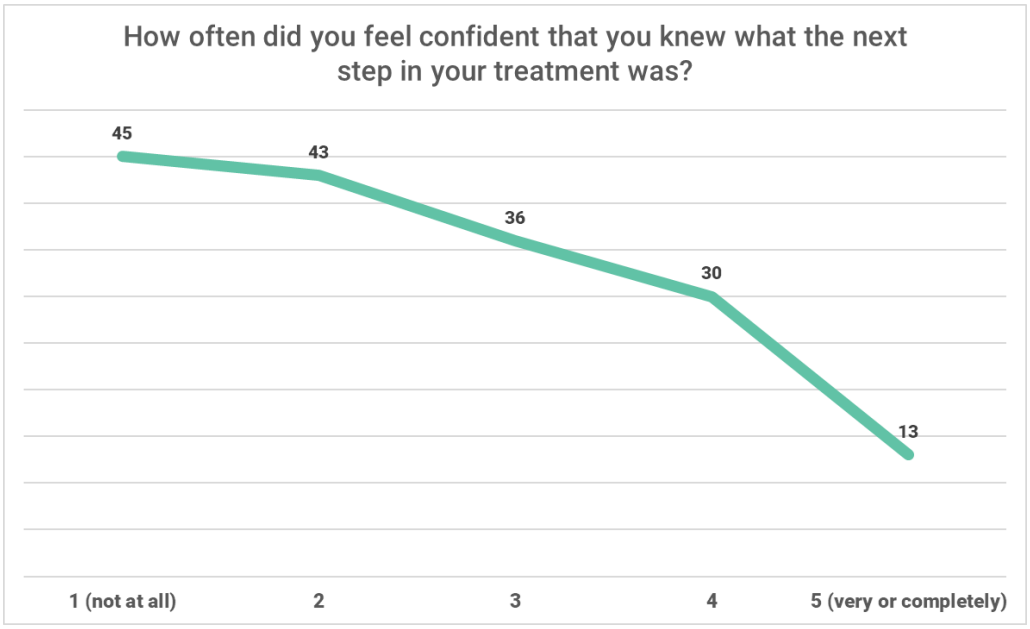
Respondents were asked to indicate which settings helped coordinate their care. The settings used were the same as those used in the previous 'Getting help' section.



The results skewing even more towards GPs for who helped coordinate care than where did you go for help shows the central role they can play in coordinating care, and that other areas who could play a role or are relied heavily upon, such as family and friends, could benefit from further support with coordination, either directly or indirectly through increasing health literacy or making the mental health system simpler to navigate and understand.

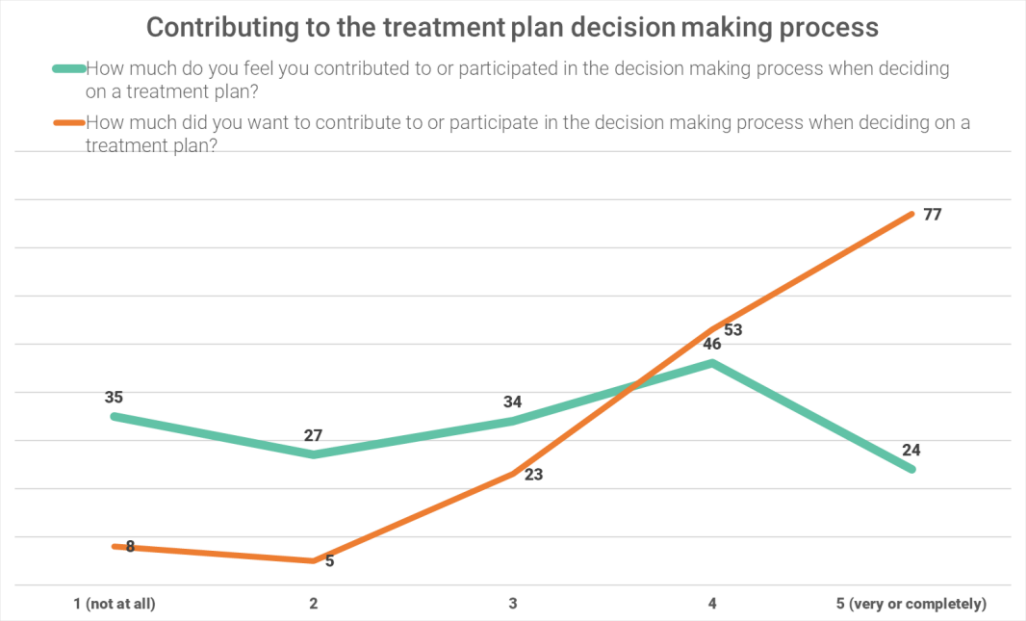
How often did you feel confident that you knew what the next step in your treatment was?

The majority of respondents did not often feel confident that they knew what the next step in their treatment was.



Contributing to the decision-making process when deciding on a treatment plan

Respondents were asked to rate from 1 to 5 (with 1 = not at all, 5 = very or completely) how much they felt they contributed to or participated in the decision-making process when deciding on a treatment plan, and how much they wanted to contribute or participate.



This clearly shows that respondents wanted to be included more than they were, but also that some felt they were included to some degree.

Further analysis on the free-text responses given in response to the question about respondents' participation in the decision making of their care will be included in future reports on this survey. Some instructive comments are provided below.

When my partner was Form 1 I had no say in his treatment, the health nurses and doctors told our family to stop ringing and asking how he was.

When an inpatient, we were not included in our son's care despite his age of being under 16. We had to push for care and to be included in it.

Family involvement is often only rhetoric, so little time

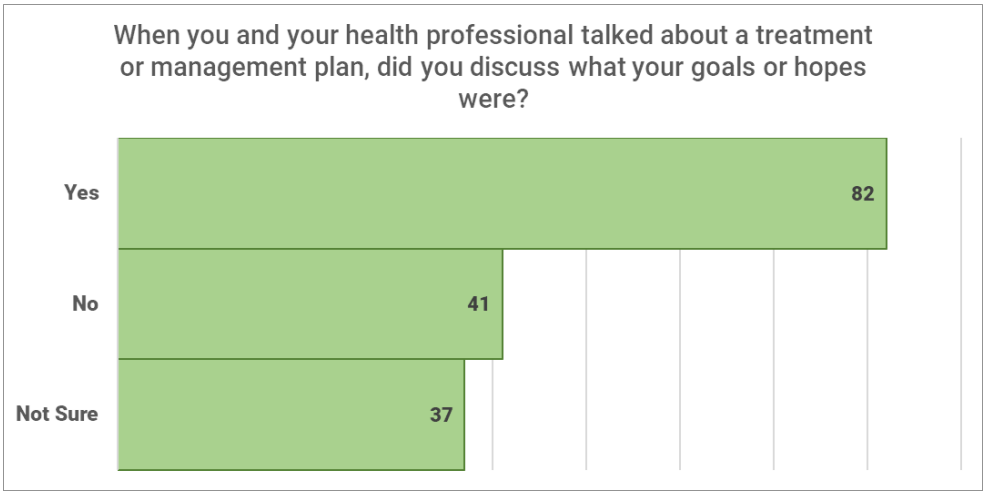
Most carers are excluded from the decision making process. It is even hard for legally appointed guardians for health matters to be included or provided with relevant information. Early on in the process, I was left to coordinate supports through trial and error.

Trying myself to get my medical information (very difficult) and co-ordinate my own care (not good at self-care, always cared for others more). Don't know what's going to happen next. Very restricted in options that I am aware of. Feel very trapped by medication dependence and requirements and Centrelink and Employment agency requirements. Overwhelmed and confused. Used to helping others, harder to help myself although need to.

I've ended up having to play a much larger participatory role in my treatment than I'd originally intended, as I've learned that I'm often unable to rely upon anyone else to do it for me, and that's pretty shocking, honestly. Still, to this day, I feel as though I couldn't trust that, if I was ever unable to make conscious decisions about my own mental health care, that I'd be able to entrust those who I'm involved in therapeutic relationships with to best uphold my interests. I've found that some treating professionals I've had to take control because they've been unmotivated to refer me to other treatment, unaware of the options that exist, or that we've had a conflict of interest or a misalignment of goals and direction. I've had tame doctors I could ask for referrals to whichever psychologist, psychiatrist, and program I wanted, and they'd write them, but I couldn't count on them being aware of any changes in my condition, or to know what to do if I was in crisis. In contrast to this, I've had doctors who have been adamant I should take the script they're insisting will help me for medication when I'm there to get a group therapy referral instead, and they've failed to see reason despite the treatment guidelines for my condition stating that medication is ineffective, whereas therapy such as DBT is effective - no apology or admittance they were wrong occurred once I provided evidence to prove that either

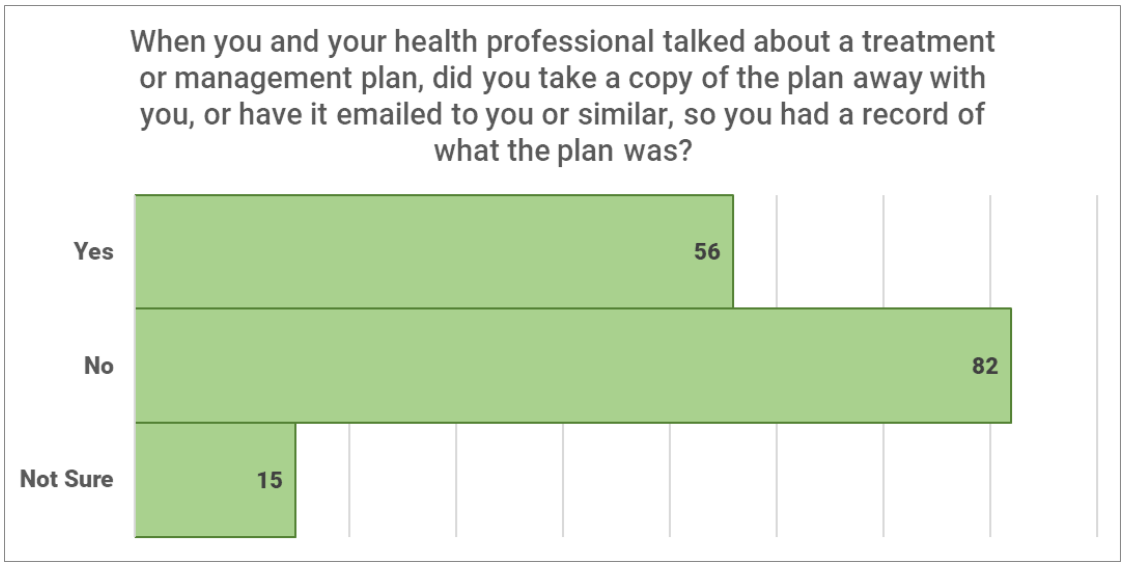
When you and your health professional talked about a treatment or management plan, did you discuss what your goals or hopes were?

Approximately half or respondents recalled discussing what their goals or hopes were with their health professionals. Given that mental health especially is a question of ongoing management and the impact on quality of life, as opposed to something that can be cured, this indicates a need for further work in this area.



When you and your health professional talked about a treatment or management plan, did you take a copy of the plan away with you, or have it emailed to you or similar, so you had a record of what the plan was?

Respondents indicated that more often than not they did not receive a physical or digital copy of what their treatment plan was.



Some instructive comments to the question asked of respondents "Would you like to give any further information about treatment plans?" is provided below:

Treatment plans are not long term enough for someone with a diagnosed incurable mental illness. The fact that after so many sessions the patient has to present to emergency department to access psychiatrist help again is beyond belief.

So much paper and so little attention to it after the event

Often excluded from the process despite consent by the care recipient or legal guardianship status

Following over 20 years in the mental health world I have never seen a completed plan. When I asked I was told there was one and that was it.

Treatment plans need to cover care of all the requirements not just focus on one aspect - which they do and say we will deal with this now and address other issues later. That is like saying we will look at the brain and the fact the heart is not pumping - well not our problem at this point, we'll deal with it later. This doesn't work - a lot of work needs to be undertaken in better care delivery by the health profession

I have been in the mental health unit of hospital six times and I have never had a discharge plan

I was never given a treatment plan, nor was a treatment plan discussed with me. Much later in my treatment and after changing health care professionals' multiple times, and self-educating so I could drive the conversation about treatment with the health care professional, I was still never met with any desire or support around making or sticking to a treatment plan

Only with my counsellor of 8 years. With any other health professional, especially psychiatrists in hospital settings when I was admitted for long periods. There was no plan to share. Just do as we say. They were the most frightening times. Not knowing what was happening

Multimorbidity

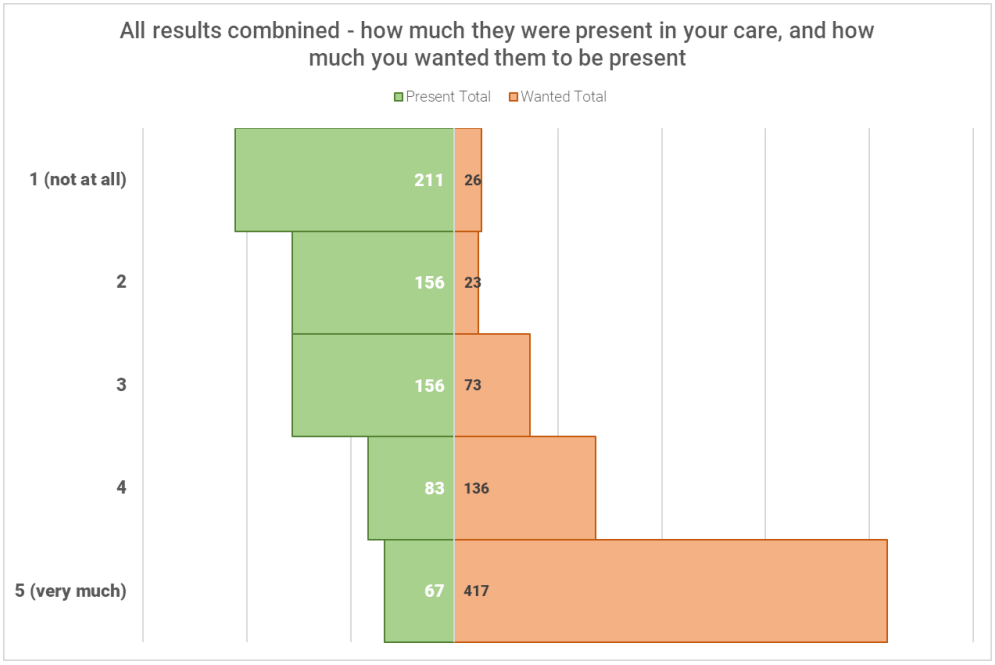
Consumers who answered 'yes' to whether they sought help for physical and mental ill-health at the same time were asked to rate a number of indicators of effective patient-centred care and broader support on both how **present it was** in their experience, and how much they **wanted it to be present** in their care.

Those indicators are;

- Complete medical history prepared with/by a health professional available to all involved in your care

- Information and interventions to **prevent adverse events** from medication interactions
- Recognition by **people involved in your care** that you had both physical and mental health issues
- Discussion with you about what **your concerns and health goals** are/were
- Understanding by **health professionals** of the lived experience of your mental and physical health issues
- Understanding by **friends and family** of the lived experience of your mental and physical health issues, and
- Understanding by the **workplace** of the lived experience of your mental and physical health issues.

Preliminary results show a clear gap between what consumers considered to be present and what they wanted. The below graph aggregates results received before 14 March 2019. In the below graph, green represents the sum of results for what respondents felt was present, and orange for what they wanted. The larger the top left in green, the more it was not present, the larger the bottom right in orange, the more it was wanted.



Consumers noted that they faced many challenges trying to address physical and mental health at the same time, and that the current system does not meet their wants and needs adequately.

Some of the comments made when asked if there was '*anything else you'd like to add about getting care for physical and mental ill-health at the same time*', and what are '*the (up to) 3 most*

important changes to the health system, workplaces or social attitudes that you think would have helped you better live with your mental and physical health issues', are included below.

There was a significant disconnect between my sister's medical/mental health support.

Most carers are on some type of pension due to looking after someone with a severe mental illness. Health funds should pay something towards gym fees to assist help reduce weight and stress. Even if the government subsided gym fees this would reduce health costs down the track for both physical and mental health.

Not many practitioners will consider anything but their own speciality.

As well as funds, time is needed to be able to access all appropriate care - this is not possible with current workplace policies. If you are a sole parent of young children it's even harder because there is only you to manage all of their time and needs for medical issues, school events and school holidays. So, while there is emphasis on getting help - the time and money involved makes it very difficult to achieve. Put stigma and isolation on top of that - makes it hard to get better.

It has been my experience that this is all but impossible.

My physical health issues were probably caused by my mental health issues, including muscular tension and digestive issues

My physical health is barely taken care of - my mental health takes up all of a standard GP booking, leaving no time for discussion about physical health, and the doctors I had been seeing never prompted me about how I was feeling physically. Long appointments were at a cost, or not possible at all at the practice I was attending, making a longer appointment impossible.

Yes, just like it took so long to get action on my depression when I got symptoms that turned out to be Chronic Fatigue syndrome - my GP actually didn't believe me that I was not suffering from my symptoms of my depression. I knew it was different. It's just like knowing the difference between your usual hay fever (I also suffer from) and catching a cold - yes they are similar, but you quickly start to realise the difference. So as much as I love my couple of brilliant GP's I have, they still didn't always listen to and believe me early on

Is there anything that's important to you about mental health care that we haven't captured in this survey?

Respondents were given a final chance to include their views and experiences as a final free-text question. Some preliminary instructive comments are included below.

The medical system has been effective .... but society has handicapped me!!

Mental health care is available through our health system, but people with mental ill health are often reluctant to access it. Mental wellbeing needs to become more commonly discussed and sought, so that people with mental ill health feel more comfortable going to seek treatments before crisis point. Mental health phone lines e.g. the Mental Health Line in NSW need to be more widely advertised as they can help triage patients who can't or won't attend hospital in person. Another thing to note is that the public mental health system is really only set up for crisis care. For longer term care, e.g. inpatient rehabilitation of even just a couple of weeks, private health insurance is required to cover the extensive costs.

Anyone with a chronic mental health condition that needs to take medication to keep them stable should be able to access a health care card to reduce the financial impact of medications on them and their families. That might reduce noncompliance in taking meds.

The challenges of rural living also place a burden on help seeking and for family have not been sought

In our case a family was blown apart and the shards are still scattered. Please consider families and consumer as part of family unit. I still reel when I look at what we went through largely unassisted. Although health professionals' clinical car was professional. Please ensure first admissions are managed with extreme care. Is it an emotional dysfunction or psychological issue or ? Have found many clinicians can be quick to medicate

While I understand the importance of, and need for, treatment and care plans and pathways, I think that mental health professionals need to be very aware that they are not treating an illness, they are responsible for the care and wellbeing of individuals, every single person they treat comes with different signs, symptoms, feelings, emotions, expectations, fears, life experiences, goals, hopes and dreams, and they need to be extremely mindful that of all the specialities in the medical field, psychiatry treats the absolute core and essence of who people are, what makes them an individual, like no other on the planet, and when, like I have experienced, they don't recognise that and treat people accordingly, they can, and do, sometimes, so much more damage than good.

Stigma and discrimination around mental illness is still prevalent within the prison population and by prison employees. Often inmates will not declare they are living with a mental illness, so treatment is not sought or provided. The individual is then released from prison with the Corrective Services in the community not aware/educated, not interested, or just too overwhelmed with the numbers of people they are supporting, so that the person's mental health issues are not recognised, and they do not get mental health support or treatment. For some individuals untreated mental illness leads to substance use, leads to crime, leads to prison. It becomes a destructive revolving cycle.

I am really uncertain about my child's support when she turns 18

If our daughter had been admitted to a public hospital seriously unwell with any other illness on 18 December she would not have waited a full month before receiving proper assessment and treatment.

Health professionals in mainstream health roles need much more education and experience with mental health

Information, information and information. That the public should know where to go to get help. Too many agencies there needs to be a more cohesive system.

Most people say talk to your GP. In some areas and in some circumstances can be very difficult to get a GP to see you at all (let alone a supportive/helpful one). Many services do not cater for sole parents/carers with Mental health issues. Need co-ordinators/integrative care support people, especially those that are the most vulnerable and dealing with Centrelink/Employment Agency requirements, complex multiple issues etc. And for people to know how to find help. Have as many different ways of helping people as possible (phone, internet, in person, snail mail, community, at home, transport help/funding to access services). Wonderful progress has been made in the Mental Health sector (especially with MH reps etc), although many improvements still needed. You can have hundreds of services, although if people cannot access them (no phone, homeless, no money, no transport) needs to be addressed/effectively actioned upon. That people know what services exist and how to access.

Ensure regional, rural and remote cities, towns and regions have sufficient practitioners so that people with mental health issues do not have to go far from their existing supportive relationships and known environment and values. Where this has to happen as a last resort, ensure the Patient Transport/Travel Subsidy Scheme adequately compensates them and that there are support liaison persons present.