



Creating positive experiences using
**NOCC Outcome
Measures**



Lived Experience
A U S T R A L I A

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Introduction

Lived Experience Australia is a national representative organisation for Australian mental health consumers and carers, formed in 2002 with a focus on the private sector. Our core business is to advocate for systemic change, empowerment of consumers in their own care, promoting engagement and inclusion of consumers and carers within system design, planning and evaluation and most importantly, advocating for consumer choice and family and carer inclusion.

This project was developed and undertaken by Lived Experience Australia Ltd in collaboration with Australian Mental Health Outcomes and Classification Network (AMHOCN).

Background

The National Outcomes and Casemix Collection (NOCC) was commenced in mental health services in 2002. Its ongoing development and review, and support for its implementation through training delivered to the mental health workforce nationally, is the responsibility of the Australian Mental Health Outcomes and Classification Network (AMHOCN)¹. The NOCC measures are mandatory and have become part of routine care, aiming to ensure that mental health services continue to understand, improve and are accountable for the effectiveness of the care that they provide.

The NOCC is made up of a set of mandatory clinical measures that clinicians in mental health services across Australia complete as part of routine care, review, and transitions in care. The measures include: the Health of the Nation Outcome Scales (HoNOS)²; Life Skills Profile 16 (LSP-16)³; and Phase of Care (FOC)⁴. The consumer-rated measures include: the Mental Health Inventory (MHI-38); Behavior and Symptom Identification Scale 32 (BASIS-32)⁵; and Kessler 10 Plus (K10+)⁶.

Collection and use of consumer-rated outcome measures, however, has lagged behind the routine uptake of clinician-rated measures. The cultural and structural barriers to why this is the case are largely known. They include clinician inertia, uncertainty about their value to clinical care, concerns about consumers' capacity to complete the measures, and organisational cultural issues that have hampered more holistic assessment and consumer collaboration in care.

Less is known about positive experiences of providing the consumer-rated measures to mental health service consumers. This could provide important impetus for the mental health workforce to increase their use of the measures with consumers. This project sought to fill this gap, and the findings will support AMHOCN to promote the value and positive use of the NOCC consumer-rated outcome measures within its training to the national mental health workforce.

1 AMHOCN (2022) Mental Health National Outcomes and Casemix Collection: Technical specification of State and Territory reporting requirements, Version 2.10. Australian Mental Health Outcomes and Classification Network. <https://docs.validator.com.au/nocc/02.10/>

2 Wing J, Beevor A, Curtis R, Park S, Hadden S, Burns A (1998) Health of the Nation Outcome Scales (HoNOS). Research and development. *British Journal of Psychiatry*, 172, 11-18.

3 Buckingham W, Burgess P, Solomon S, Pirkis J, Eagar K (1998). Developing a Casemix Classification for Mental Health Services. Volume 2: Resource Materials. Canberra: Commonwealth Department of Health and Family Services. Available from: <https://www.amhcn.org/publications/developing-casemix-classification-mental-health-services-volume-2-resource-materials>

4 Independent Hospital Pricing Authority (2016). Australian Mental Health Care Classification: Mental health phase of care guide Version 1.2. Independent Hospital Pricing Authority, Sydney. Available from: <https://www.ihpa.gov.au/publications/mental-health-phase-care-guide> accessed 25/1/2020

5 Eisen, SV, Dill DL, Grob MC (1994). Reliability and validity of a brief patient-report instrument for psychiatric patient outcome evaluation. *Hospital and Community Psychiatry*, 45(3), 242-247.

6 Kessler RC, Andrews G, Colpe LJ, Hiripi E, Mroczek DK, Normand S-LT, Walters EE, Zaslavsky A (2002). Short screening scales to monitor population prevalences and trends in nonspecific psychological distress. *Psychological Medicine*, 32(6), 959-976.

The aims of the project were:

- To seek the views and expertise of mental health consumers with experience of the NOCC measures.
- To understand better the positive benefits of the consumer-rated measures being used in routine mental health practice.
- To understand how positive feedback on the use of consumer-rated NOCC measures can inform training for mental health staff, in order to promote their wider use within mental health services.

Data Collection

In December 2021, a small group of consumer and clinical advocates participated in a focus group, and follow-up discussions to refine the questions that would be best to ask consumers about their experience of the measures. The AMHOCN consumer project officer then used these questions to conduct in-depth interviews with 10 consumers, drawn from across Australia, between December 2021 and March 2022.

Data Analysis

Thematic data analysis of the interviews followed the steps recommended by Braun and Clarke.

The research team independently coded each interview, then held a series of data analysis team meetings to discuss the codes and themes emerging from the data. A constant comparative approach, supported by robust group discussions enabled the research team to reflect on and gain an in-depth understanding of participants' experiences of using the measures.

Ten consumers with lived experience of completing outcome measures associated with their mental health were interviewed. Participants varied in age, gender, location and mental health conditions.

Four main themes were derived from the analysis of the data. These are described below, with the voices of consumers (through direct quotes) provided to highlight their experiences in detail.

Theme 1: Help me complete the measures

All participants spoke about the challenges they faced when completing the measures and how their personal situation and preference impacted on their completion of the measures. Three subthemes were identified: 1) Think about what is going on for me the first time using the measure; 2) Helping me at a time when this is difficult; and 3) Preferences when completing the measures.

1.1. Think about what is going on for me the first time using the measure

This subtheme included participants' trepidation when first given the measure and their reactions to completing it for the first time in the context of seeking help from a health professional for their emotional unrest. Most participants expressed feeling unprepared, not knowing what to expect, feeling a sense of not being in control of what happened next. Several participants described their first experience as confronting, scary, confusing and dis-empowering.

Yeah, I felt – well I think the first one with the piece of paper, I thought 'oh okay, well this is normal, this is a regular thing; he's got that piece of paper, but it must be a routine kind of procedure that they're doing'. And in the conversation, I felt like he was – yeah, maybe I did feel a bit ripped off ... It was kind of good and bad because I thought 'oh well, good we're doing something about it, but it didn't seem as personal then, because I thought we were just having a chat'.

When I first started seeing her or first started seeing any psychologist really, I remember you got given all this paperwork, all these forms and usually you just fill them out. No-one really guides you through them or tells you what they are, and I guess it was a really intimidating process. It's like clipboard, pen, fill out these forms while you are waiting.

I think people assume or think 'Oh she has high health literacy; she has a high level of understanding; cognitive ability; she doesn't have any learning disabilities'. So, they probably just think 'oh well if we give her the form, she will be all right, she will do it by herself'... I think that there is not really any kind of thought put into, that some people may need some extra assistance or scaffolding to fill out these forms, especially if they have never been to a mental health service before. In saying that though, I have had some clinicians say if you need any help just ask for help, just ask questions.

Sometimes you don't have that relationship built with the clinician yet, and so it's just really weird for them to come in and even though they themselves aren't asking you this very personal question, it's awkward that you're just sitting there quietly, and you're doing like this, just test sheet, and saying these really personal things like often it's like you know you're declaring a lot of risk ... I'm very anxious as a person meeting new people and being in new environments is really terrifying for me. So, I like to just be accommodated with the things around me and be aware of what's going to happen before it actually happens. So, sort of springing a test on me is quite scary and I think I prefer to do that maybe like via email in the comfort of my own home. Before I attend the service, because then I sort of feel like I don't have another choice.

“No-one really guides you through them or tells you what they are, and I guess it was a really intimidating process”

I also feel really bad because, all they're doing is just waiting for me so I just feel like a pressure to hurry up and complete it, even though I know that it's their job, yeah I don't like being observed a lot of the time or feeling like I'm a burden ... But either way I'm just sitting there freaking out the whole time ... you just feel like you're going to fail and disappoint everyone that you know that's what it feels like; like, I don't. I'm sitting there expecting the worst like I'm just gonna get some security guards and come in and be like this person's not well enough or is too well for this service, you know, there's just a lot of that sort of contradictory nature. Then you just feel very self-conscious, I think. Yeah ... Or turned away like it doesn't feel like you feel like. Either way, you're going to be in a bad place.

It was very confronting ... Because you have to sit and analyse exactly how you're feeling, you can't hide that and you do feel exposed, so as much as you feel exposed to talk about it. To actually write it down or how you're feeling.

When I saw a new GP who didn't know my history and didn't know my background and I saw a one-off psychiatrist at the hospital who knew absolutely nothing about me ... Not my GP who I've been seeing for many years. There is a point to it, you know, but yeah, I didn't see that at the start. The first few it was just like 'oh God's this form again. What is the point? I don't get this', but now I sort of see the value and see the point in it.

Some people's levels in literacy are nowhere near the level that it needs to be for the questionnaires. And often that is definitely the case in youth mental health ... it's not even accessible to people whose first language is English sometimes ... If you're given a physical form as well, the fonts are too small or the presentation of it isn't accessible or it's expecting people that don't have fine motor skills to pick up a pen and do that.

Yes, but probably not in the first session because you're feeling so vulnerable in the first session anyway. Uh, and you've gone to see somebody because you need help. I think when I did it in the first session, although that you want to put a lot of emphasis on it, it kind of brought up a lot of things for you and a lot of feelings for you because you're so vulnerable and you are feeling the lowest of the low. So, all your answers will be on the negative scale.

All they're doing is just waiting for me so I just feel a pressure to hurry up and complete it... I don't like being observed a lot of the time or feeling like I'm a burden ... But either way I'm just sitting there freaking out the whole time

1.2. Help me at a time when it is difficult

Several participants spoke about the experience of completing the measures at a time when they were struggling. Participants emphasised that they were often asked to complete the measures at a stage in the help-seeking process when they struggled to read the questions, to hold a pen, to concentrate, and to write their responses. They described this as a time when they felt confused, overwhelmed, or agitated and might not be able to find the words to describe what was happening for them, to see clearly or fully acknowledge what was wrong or its cause, and what they needed to do to alleviate their distress. Despite these circumstances, participants also described how completing the measures was a helpful start in giving some order in the confusion or chaos of how they were feeling at that time.

I think the hard thing – I didn't realise what it was, I was just angry, really angry, and that's how it came out. And I don't know, it was just through that tick box with the piece of paper there that, oh, I've got depression ... Whether he [GP] knew what he was looking for, but I guess that's why he got the form out. Maybe I did know, but I was just focused on my anger and irrational irritability and all the other symptoms, I wasn't focused on depression, I just wanted to feel better.

Really, when you're in it, you don't know how below the horizon you've sunk ... And maybe doing that questionnaire, it has been kind of reaffirming to think, yeah there is a reason why.

It was just on a piece of a paper and it's a combination of me feeling really shitty and the form really crammed, because when you have anxiety when stuff – like forms are busy and overwhelming like and you're already agitated it just spins you out even more. You have to have really good attention to detail for some of these forms as well if they're super crammed and busy – can be confusing.

The survey gives kinda like a clear indication ... where you're moving to ... where do you want to be? What are the things you want to work on? But sometimes when you're deep down into despair, you don't know what you need to work on. You're just surviving.

You know you walk in there or you have a session like this or on the phone and they only get like a snippet of it. There's only so much that you can say about your condition, particularly when you feel like you're at the very start of it when you can be resistant to treatment. You can be a little bit reluctant to acknowledge yourself what's going on, and I think it does help them. I mean, in my experience, I think it gave them a much deeper picture of what was going on when I was little hesitant to verbalize at the time, yeah.

[Did you sort of come to realizations about things that you hadn't thought about before?] Probably that you're doing better than what you thought or actually maybe you're not doing as well as you thought ... maybe that you should seek other help as well ... the other things that you could probably do when you don't even think about stuff like that.

I've always really experienced filling them out as, 'oh God is this the bloody form again', but then I also can do it, do a check in and go 'actually, but this helps them to know where you're at, so just bloody fill it in'. And sometimes it's actually useful because you haven't done your own reality check and you're just too busy blundering on to do with the reality check and see that you're either going down or going up.

*I went away in complete denial... 'You think I've got what?' ... And I'm like, 'Yeah, man, not me. No sorry' ... I was actually seeing her for what I considered sort of, problems with hormones for want of a better description, and it was here that she said, 'Have you ever thought that this might be bigger than just an imbalance in your hormones?', And I was like, 'yeah, nah Oh, good'. And she's like, 'Yeah hang on a minute. And have you thought that this [might be a mental health issue]', and I'm like, no ... It's really interesting the messages you just tell yourself, isn't it about it all, with doing the K10 and then this is what it is, this is what I think it is, was a real sucker punch for me, 'cause. It was then 'I don't do depression. I'm super strong and super independent. I can crack on with life. This **** isn't gonna affect my mental health. I can deal with this ****'. So, it was a bit of a sucker punch. Yeah.*

If I am presenting in crisis or if I'm having lots of suicidal thoughts that then becomes the priority, and interestingly only recently I was really struggling, and she got me to do the forms – she sent them to me out of session via email. She said I am not going to give you the forms now because you're in a state of distress and crisis. She is like 'my main priority is to help you through this crisis and when you are feeling up to it could you please fill out these forms or send them to me via email?'

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1.3. I have my preferences

Participants described a range of personal preferences for how, where, and the context in which they completed the measures. This included the location, whether the health professional was present at the time, timing, and the format in which the measure was offered. Participants' preferences varied and this was usually related to how they perceived their needs at the time.

So sometimes questionnaires, like on paper, don't really work for me because I can't read a lot of it sometimes just depending on like my level cognition on the day.

It's a hard question to answer because depending on my mood I suppose, because at times when I was really bad I would prefer them just to do it and read the questions to me. So, I don't have to read and concentrate.

I appear very high functioning and so, people just, you know, assume that I can engage with things that are generally quite near typical or like the traditional form of filling out a survey with pen and paper. But sometimes they don't see the panic attack that's going on and me not being able to read the one sentence it's just, yeah, it's a lot.

It's better if someone you know does it in a conversation rather than writing up. Multi-modal and having options is really big to me.

My experience with all the clinicians has been, they sort of step away from me and give me the time to fill it out ... I like that they are giving me the space to sort of think about it.

Having it in a written word, I think was not as confronting that having someone ask.....Depending on who's asking the questions or saying it, I mean, like my first psychiatrist. She was just so matter of fact, I didn't like the way she asked the questions. It just felt really cold. And then I was a lot younger and more sensitive ... Yeah it felt a bit cold and rigid with her, felt very, well I'll use the word, like 'clinical'. It's very, very clinical and I didn't feel like I was a person. I just feel like I was just an illness ... [speaking about another psychiatrist] He was, straight, but I felt like he still cared ... I actually appreciate his character because it was a bit no nonsense but still, it was validating as well, which was really good.

When you read the question, it's a bit easier to dismiss I think, but if someone is actually asking you – you know, real deep questioning, you know?

No, I think there is that bit of get to know them, get to know you, especially with a new clinician. They will have a little chat with me and then pass the form over to me. It's not like 'Bam. here we go, we're gonna assess you now based off this one form and then we'll get into it.' There is a little bit of a meet and greet there and that just to see where you are at in a non-formal format.

Tell me why I need to fill in this form. How is this going to help me in the moment? How is this helping me right now? When I'm feeling all so lost and don't know what I need. So, I used to think why. Why am I filling in this form? I didn't see the point in it at all.

Some participants spoke about the importance of the physical environment in creating a sense of comfort and safety when the person is completing the measures.

I feel like the environment is not really considered that much because, I'm a very sensory person, so I'm very sensitive to people around me and things, and noises, and lights, so I feel like that's something that needs to be thought about ... And then when they came in they handed it to me on an iPad which was really good, and so I could just submit that and then that was it. And so there wasn't any paper floating around. I didn't have to use pens or anything, it was just super like that. That was probably about my best experience of it.

The doctor is sitting there, they're not... you don't have that pressure of answering verbally if that makes sense? You know you're in your zone answering your questions with that.

[Do you think the physical environment is important where you're filling it out?] Yes. I've found myself to be a lot more comfortable in a non-clinical setting with all my health supports across the board, and I am much more comfortable in my GP's office where I know the environment ... My GP's got a photo of her kids above the desk. You know, I know the space. When I've been in a hospital, especially mental health like in outpatients, it's a room that's designed for people not to harm themselves, so there's no table. There's blue wipe down tiles that you know, it's very, very clinical and confronting. I felt very uncomfortable in that environment. I thought even just a cushion on the chair would have been great.

Some participants spoke about a sense of dis-empowerment they experienced that came with the health professional being present in the room when they were completing the measures.

There have been some clinicians who sit you down, they give you the paperwork while you are in the room with them ... and then there's just a super awkward silence as they are watching what I am filling out. It makes me feel really anxious for someone who has anxiety. So, I don't like that. I just say 'can I go and sit somewhere else?' But you have to have the autonomy to do that though.

Normally it is with them there, and that would not be my preference most of the time ... It would normally be if they give it to me before I came in, or just give it to me with a lot of time beforehand and let me fill it out by myself, and then come to them if I have questions. That would be really great because if they are there with me in-person I feel very pressured, and it feels sort of like a test ... I think because there is often a power dynamic between the person who gives the questionnaire and the person who is doing it and it does sort of feel like an examiner and examinee relationship ... whatever you write has a reflection on one party, so if I write like I'm declaring some sort of distress there, or I feel like the service that they provided isn't adequate, I'm making a comment on one of us and it is very personal. It doesn't feel appropriate for them to be there.

I've found myself to be a lot more comfortable in a non-clinical setting with all my health supports across the board, and I am much more comfortable in my GP's office where I know the environment

Other participants expressed having no problems with the health professional being present when they were completing the measures.

It often feels that I have a limited amount of time to get whatever I have off my chest and for them to do this assessment. 'Let's just get that out of the way so that I can then relay what I need to get off my chest and what we need to talk about in the sessions'. Because yeah, it's very limited. Usually about a one-hour time frame so if I can whip through this assessment they know where I'm at. I'm getting the results straight away and then we can get right into it.

I think that she genuinely uses it as a way to ascertain how I've been travelling and where I'm at, because you can get a lot of information from one of those forms a lot quicker than you can by potentially having a conversation if you know what I mean ... I think if they are used in a combination with conversations and verbal discussions as well as the questionnaires, the forms, they can work really well together on someone's treatment. You can't use them standalone is my opinion.

You don't want to have the thing where the clinician goes through every question and then you do an answer and question. You wanna have an open and frank discussion ... you would hope that the clinician wouldn't go, 'right question two' and then start the discussion from the survey.

Of note, some participants said that they had not been consulted or included in decisions about how the measures was offered or used.

[Has anyone ever asked you?] No

I've never had one pulled back out in front of me and shown to me.

I think that she genuinely uses it as a way to ascertain how I've been travelling and where I'm at, because you can get a lot of information from one of those forms a lot quicker than you can by potentially having a conversation if you know what I mean.

Theme 2: Explain what is going on

Participants described their experiences of the various ways that they were offered and then used the measures with health professionals, and how this then influenced how they engaged with those health professionals. Two subthemes were apparent: 1) Not just an administrative exercise; and 2) Explaining the purpose is important.

2.1. Not just an administrative exercise

Some participants expressed clear concern that completing the measures be not just a one-way administrative exercise that served the needs and requirements of health professionals and their service funding and reporting requirements. They stressed some scepticism about the purpose of the measures, particularly when the person was not included in discussions about their purpose, and when there appeared to be minimal discussion with them about the measures once completed. They perceived that these behaviours by health professionals had negative consequences for engagement and were a missed opportunity for building a trusting relationship.

It makes me feel like the filling out the questionnaires is meaningful, like it actually means something that it's not just because I have worked out that she has to – I'm assuming she has to do this because the minute you involve Medicare and the mental health care plan and they've got reporting. I don't know if they have KPIs, I mean I am not a clinician, but the cynical part of me is like she's only (clinicians or psychologists) only do these questionnaires because they need tangible quantitative data.

[How did that make you feel to have the health professional ask you about the scores?] Someone actually reads this, like people actually read it and care. Like you know the cynical part of me thinks that you just get given these forms because it's a KPI or it's mandatory or they have to do it because they're a government service or it's part of their accreditation process or something, like we've got to give the consumer this form but when they actually report back on it and use it it's like, well actually it's meaningful.

Come with a little bit of shared lived experience. Or just acknowledging that that sounds difficult or something, rather than zero response, yeah, because most questionnaires hasn't you know. It's either if the clinician's doing it with you often, it's just very militaristic and very efficient, and that can seem really scary if someone skips over something that is very personal to you and you feel like you've disclosed something very big and they're just like, 'OK, next'. Yeah, so, it's nice to take time.

[Have they ever done it, where you felt that they're trying to get to know you better?] No. It's always been them trying to get like that, they're trying to get information from me for their benefit.

With you know peer work and lived experience work, we're often trying to walk alongside the people that we're intending to support and we're exploring it together and I feel like it's a missed opportunity if you're going to, just use a sort of survey or assessment to have this one-way relationship.

I wanna feel from the clinician that they want to be there, that they're not just doing their job. I don't want to come in like [Mechanical manner] ... I think kindness comes with honesty, integrity, sincerity.

It sort of seems run of the mill and it's just part of the procedure and they need to do it in order to get to the talk therapy or to what they actually want to do. So, it feels very standard Doesn't feel like either party really wants to be there.

She said this is what we need to do as part of our paperwork and you know the monitoring and stuff. So that was fun and she explained it all to me.

This form is for me to determine where you're at. So, I can better help you so I can direct you to clinician 'A' or clinician 'B' or I can give you a prescription for medicine 'A' or medicine 'B'. Or, you know, we can talk about it, or you need to go to the hospital right now, you know.

The clinician has to be mindful of the way that they approach discussing the responses that the consumer gave to the questions.

I think it's also really important that the people who give the consumers and carers the forms, when you receive the forms back your body language is super important. So, I have never had my psychologist get the forms back and be shocked or show anything or be like 'oh my gosh, like wow this is terrible'. There has never been any kind of reactions like that. She is just literally so neutral about it. I would give her the paperwork and she grabs it, scores it, and she will make a comment usually and it's usually like 'oh I see things haven't been going great for you' or sometimes she even asks about 'what do you think about your scores?' or 'where do you think things are at?'.

The other thing though is when my results have improved quite significantly, she will usually, well most of the time, she will acknowledge that ... Sometimes she will give me a reward because we have this thing. So, at the moment it's stickers. It used to be highlighters; it used to be Tim Tams; it used to be peanut butter Oreos – now it's stickers. We give each other a little like gift. So it's mutual. Because we are both in this together. We are walking along this path together.

2.2. Explaining the purpose is important

Participants emphasised how important it was for the health professional to explain the purpose of the measure upfront to the person. This helped them to feel less confused or overwhelmed, have a clearer sense of what to expect from their interaction with the health professional, and to understand how the measure might benefit them.

'You have been referred here by blah blah blah because of blah blah blah, and then we have got some outcome measures or some tools that are going to help us understand where you are at, at the moment, and then we can use them later down the track to see if things have improved, and if we are using treatment, if the treatment we're using is right for your needs'. So, kind of introduce it, so how is it of benefit to me; how is it of benefit to my recovery? How is it of benefit to me coming to the service? Because otherwise it's like 'why are they giving me these questionnaires, what is the point of them?' Someone needs to actually sit down and explain the purpose of them; how they're going to be of benefit, and I always like to know when they're going to be reviewed, or what happens once I have done them? Like if I score really high on certain things does that dictate the amount of treatment I will receive or anything like that? So ideally just having that conversation where I can ask any questions or clarify anything, then I am left alone to do it so I can take my time and not be rushed and not feel pressure, and then coming back to the clinician and saying I have filled these out, I just have this question, or have I filled it out properly? That would be my ideal.

I'm sure there's some people that hate them. Like I'm sure there is some people out there that find them really invalidating and frustrating, but for me once I had an understanding of the purpose and how they can be useful to me and my journey and that they are for me, I actually started using them in the way they were meant to be used, but I had to have education around that ... Once I developed an understanding of how they could be of use and how they were beneficial really helped me engage in the process. I think conversation, explaining that these are actually reputable tools that have been developed by experts, and these will help us understand how things have been for you over the past week or the past couple of weeks, and you might not be able to tell us verbally or you might not be in a position where you feel that you want to disclose in that way, but this is another way. It's another way of telling your story and where you have been.

Once I had an understanding of the purpose and how they can be useful to me and my journey and that they are for me, I actually started using them in the way they were meant to be used, but I had to have education around that.

Theme 3: Being honest with yourself and others

A prominent perspective expressed by almost all participants was in how the act and process of completing the measures inherently challenged and confronted them to be honest with themselves and others about their circumstances. This occurred whether they were completing the measure alone and in private, or whether they were completing it with the health professional present, or when the health professional was asking them the questions directly.

[Why do you think it's easier to fill out with another person?] Because I think if someone actually asks you the question – when you read the question, it's a bit easier to dismiss, I think, but if someone is actually asking you – you know, real deep questioning, you know? ... it's different in your own voice to read the question ... Sometimes your first response isn't, like, your first instinct may not be the real answer.

I prefer hardcopy, yeah ... It's confronting, but it makes you feel like you're doing something worthwhile, whereas on your computer, how many surveys do we fill our computer 'tick, tick'. It's easy just to go down the middle '5555' you know or whatever'. Whereas, when you're actually writing it down, it's on a hot piece of paper. Yeah, I think it's more worthy.

I think, especially when it was the more severe time, it was like, oh, you know this is bad, like this is, it's kind of like you want to select the lower number, but being honest with yourself is the only way to get better you know?

With a survey you can't put on a face ... It kind of makes you sit and think, but how actually do I feel? And then it actually, you know, it makes you put the truth down because you're actually thinking, I know I've got to put the truth down. You know this is how I feel. Yes, I feel suicidal or, but do I feel suicidal at other times? No. But at the moment I feel it, yes, do I need to be hospitalised? No, but do I feel I may need to be hospitalised. So, that's the thing, it's like sometimes you 'Yeah, yeah, yeah, I've got the great support. Yeah, I'm struggling but I'm doing OK'. Whereas the survey, kinda like you can't say that.

[How do you think clinicians know how things change for you in terms of your mental health?] I think the only way they do know is if I let them know, if I share with them, and I'm truthful in my sharing.

“With a survey you can't put on a face... It kind of makes you sit and think, but how actually do I feel?”

For some participants, it helped them to be more honest than they might otherwise have been. Whereas other participants also emphasised the importance of feeling safe to provide accurate responses. Across the variety of comments, what was apparent was how each participant tossed over the decisions in their mind about how they should answer the questions, and how they actively thought about how their responses would be received by the health professional, being concerned about coercive treatment if they did disclose their true level of distress, and what the consequences of being truthful might or not might be.

I think something that needs to be conveyed to consumers, carers – the people who are actually filling out the forms, is there is no real benefit in lying or it's not a judgement tool. I think you really need to stress it's to help you as an individual, because I remember when I was 15 going to a public youth mental service I actually – I think I had the SDQ, the Strength and Difficulties Questionnaire, and my first appointment I had got given I was freaking out and I was anxious, and I didn't know what the service was. I had just been referred by a GP and I remember for every question I put the answer that was less severe. So, say I wanted to score a 3, I actually scored a 2 because I was like, I don't want them to know that things are really this bad, I wanted to pretend that things were better than they were, which in hindsight was actually detrimental to me. The only person I was doing a disservice to was myself, like it didn't affect the clinician. She is not the one receiving the treatment or that's here because she has mental health problems, you know, and I just did that a couple of times and I wish I hadn't. I just wish I had had more education or more of a conversation around the forms and the purpose and the use of them.

I don't feel like there's any shame there but other people I'd imagine they would sort of hold back a little bit and there might be people, that maybe exaggerate because they think that they might get more help or quicker. But yeah, as long as the people filling them out it wholeheartedly and honestly with themselves and sitting there thinking about what they're filling in. It's a great tool.

Be more consistent across that, all of the clinicians, just to have a similar procedure so it is regulated a bit better because I think it can be quite emotional and traumatic for people to be confronted with the questions on the form. We both said actually about getting to know the person as the first thing before giving them the form ... With that safety comes honesty ... if it's a safe space and you trust that person then you're likely to be more honest.

It's a missed opportunity in the sense that with the GP, when the GP's going, 'so tell me what's the answer to this one', she's almost getting yes, it is data, and she's getting it is a tool for her to get that data side. But she also used it as an opportunity to explore further and open up the conversation further, [GP said] 'So well, hang on a minute. That seems pretty low since the last time we did this. What's that all about? What's going on? Is there something else changed?' ... You get more out of me. It's more. It gives you more.

I can't tick a box and feel fully confident in that because my experience shouldn't be sort of put in a box or labelled like that. And for me there's a lot of impostor syndrome with even seeking help. I'm not sure if they were understanding, not sure if I'm communicating it the right way, and I feel like distilling it down to something as simple as like, a multiple choice thing or expecting me to write things as words when I find it hard to communicate with words. And that's, yeah, quite invalidating.

The Impostor syndrome will come in when I'm actually feeling about eight, but I'll tell myself to put like a six because I think that my problems are less important than other people's problems, like I don't wanna get prioritised in front of other people. I don't feel like my eight is maybe someone else's eight, more as like an objective eight. That's just how I'm feeling. And so I will, you know, put less on there. Either because like I feel like other people deserve the help more or because I'm scared of being like, restrained or you know, any sort of involuntary treatment is a really big thing, or I'm just not really sure what they mean by the questions sometimes. So, it's not very accurate of my actual presentation.

“She's getting it is a tool for her to get that data side... but she also used it as an opportunity to explore further and open up the conversation further.”

I am not, I will not tell you the truth. I think about being dishonest. I don't feel safe and I don't think you're motives are good that you're gonna protect and care for me. So, I'm not gonna tell you this because I know.

*It is very important how it's introduced, you know the way that you just said there [little dispassionate role play introduction], how do you think it would have happened if it looked like this? My daughter would have gone '**** you!!' Actually, I would have. I would have done the same.... And I know my husband would have done the same because it's like 'You actually don't give a **** about what I put on this form. So, I'm just gonna write any old ****shit, quite frankly.'*

3.1. Putting my feelings into a clear context

Participants described how the results from the measures served to validate their feelings and lead them to recognise that they were experiencing a mental health condition. They described this as a relief to finally have an answer, or diagnosis, to explain what they had been struggling with. Completing the measures was an opportunity to reflect and realise, an 'eye-opener', providing them with answers that then made sense to them, and that they could also choose to share with others.

... [it helped you appreciate that you had depression?] Yes... he was putting it all, kind of, into context and sort of giving a reason for why. So, I guess as much as it brings you down, there's an explanation for it, so it's not this 'why am I feeling so crappy?' It's, well, this is why. So everything is kind of a mix, it's good and bad ... but I think it wasn't such a surprising big thing, it was more a relief to say yes, I feel like this, I can stop pretending ... all these things are stuff that you generally try and hide ... It was kind of a relief to say, 'yeah I'm not doing well in these places' ... I knew I was going there for help, so it was just part of that.

I think it's a different way that you think about yourself.

Sometimes the questions do make me think, like, I have to go back and you think 'yeah maybe I have been more agitated because of this and this'.

It helps me to conceptualise where things are at, I think, because to me I find it validating. It's a validating tool.

It was a bit of an eye-opening point for me ... 'Oh wow, I actually don't feel that way. I've actually been doing better than I thought'. So, it is a good reflection tool as well.

It was, I would say, bittersweet the first one. Because in a way I was thrilled that I had a diagnosis that it wasn't just me being a bit loopy. Crazy because I thought, you know, I thought I was a bit, like off the planet, because I'm such a 'normal boring person' and I was so frightened by going crazy ... It was hard to hear, but also, and that's being honest, with hard to hear it also in a way, a big relief as well to know that I wasn't going crazy, and then I had a diagnosis, and it was a condition of mental illness like any other illness.

I think especially when you're in a crisis situation, it can be confronting because you're finally seeing; it's on the paper. It's written in front of you or said to you, depending on whether it's like a face to face or a telehealth. Whatever the case may be, it can be difficult to sometimes get to the point of verbalizing it or seeing it on paper. I mean, I know for me it's quite confronting because until that point, I guess I was very resistant to treatment. I didn't want to admit that I had the problem, so then saying it out loud or reading my own responses back; or having someone reflect it back was tough.

“It was more a relief to say yes, I feel like this, I can stop pretending”

It was a bit of an eye-opening point for me as I improved to sort of look at it and go, 'Oh wow, I actually don't feel that way. I've actually been doing better than I thought'. So, it is a good reflection tool as well, especially if you fill out so many yeah. [8]

I sometimes, I need that check in and sometimes you can have an overarching emotion, but this helps me break that down into little bite size pieces as I answer them. I am also able to use it to flesh out, let's say, in a diary or with your email, when I want to send to one of my support team to really tell them how I'm feeling. [9]

As the below participant indicates, in part, the consumer's ability to use the measures to put their feelings into context may be determined by the way the clinician introduces the consumer to the measure.

No, I'm not. No. It's always been them trying to get like that, they're trying to get information from me for their benefit. Yeah, not me. Understanding myself though. [3]

Some participants described how they continued to use the measure as an ongoing self-care tool, so that they could keep track of themselves over time, and also to take charge in informing their health professionals about how they were faring and prepare better for their contact with the health professional. Used in this way, they saw the measure as a means of practicing early intervention for themselves.

So, it depends on the context and who you're seeing – why - the first time - the relationship. And yeah, and the intent of why the tool is being used as a tool, but it can be used in various ways. I have used it for myself, personally at home without a professional, just as a way of zoning in on my own mental health ... I am also able to use it to flesh out, let's say, in a diary or with your email, when I want to send to one of my support team to really tell them how I'm feeling. [9]

And I don't wait for a crisis point. It's a way to intervene and a check-in system to take stock of how I am. Because I'm high functioning, it's very easy to go go go go for me easily without, just go through the motions and be very disconnected from my actual real emotional state. So, this for me is a tool as I start seeing those signs of burnout and being tired and getting snappy, I'm getting. [9]

And there was quite a conversation then about what depression can look like, so- ... an explanation. And the other situation was that a GP that is my regular GP who I go to all the time, and I had been on and off on medication, and psychologists, and I realised I needed to get my head together again, I'd gone to him saying I've noticed changes, or I've noted deterioration. And then he asked the questions. And that was the one where he kind of slipped it in. I didn't realise we were doing it until I got to about question four. [1]

But sometimes with the nature of my mental illnesses, especially the depression, it can make you feel like things maybe potentially a lot worse because you are over-thinking and you have just got stuff ruminating in your mind, and so you think 'Oh, things are really shit', but once you do these questionnaires and like 'Okay, well maybe things aren't as bad as I thought they were'. [2]

I usually do them right before the session and send them through and then I was able to like specifically hone in on this in this session today, so I like to write it down. It does help to sort of generate and jog your memory, yeah. When you reflect back right over that time, if it's like 2 weeks between or a month between, yeah. [6]

One participant, however, made the observation that they were already aware of how they felt and were simply documenting those feelings using the tool.

I honestly think I know how things are going before I do the tools. Like I have a pretty good insight and I mean I have been unwell for a really long time, but I have a really good understanding of when my mental health has gone down the tube a fair bit. So, I think the tools just kind of reinforce that because these tools are really valid.

3.2. Taking control

When the health professionals were seen to actively use the outcomes of the measures with the person, this was also perceived by participants as very empowering.

And it did help at the time that it gave me a feeling of proactiveness or of doing something.

I think it gives you... It has to - I don't know how to explain it... like, you're taking the wheel there a little bit I suppose. And it doesn't sort of, you're guiding that you don't get any sort of outside inputs. The doctor is sitting there, they're not... you don't have that pressure of like answering verbally if that makes sense? You know you're in your zone answering your questions with that, you've got the wheel, like you're in control that so that's an empowering thing I think that's good.

I was well aware of it, so they were very transparent about that, which is very important, and it also is for me personally, I know that may be different to other people. It was kind of good when I was in that crisis situation that made me feel like I didn't have problems filling out that form, if that makes sense?

In some ways, when I was filling it out and then it got better, like especially when I had made a significant difference, for a brief moment can be exhilarating. Saying that, 'You know what? Damn it. I'm getting there', you know, right? Because when you're in the darkness, you sort of think sometimes you're not gonna get out of it.

However, some participants also expressed awareness and concern for the potential inherent power imbalance between them and health professionals as part of help-seeking and the process of completing the measures. They described this arising from the limitations of the measures which they saw as largely determined by health professionals and coming from a clinical perspective, not holistic.

You kind of know that the person that you're talking to is aware of a lot of the answers, and so I think, apart from you know, obviously there's the power differentials that come with roles, I'm being like the help seeker versus the helper, but they're holding a lot more cards than you are. They know these like very personal things about you already, and there's that power differential going into it from the-get-go.

[So do you think that when the clinicians, when they were filling out the survey or questionnaire, do you think it gave them a better understanding of what things are important to you?] Generally not, because they don't ask the right questions. Like, they ask the questions that you know that sort of tick the KPIs, that they need to address that are often from diagnostic statistical manuals or are from some hospital procedure. That's part of their funding, but it's not really humanistic and individualistic, it's not about, you know, what does this activity mean for you? What does wellbeing look like for you? It's not as broad as that, and giving, you know us people with lived experience the chance to identify where the topics are based and what we want to talk about. You know because it's them giving us the mould to fit into to begin with.

I think because there is often a power dynamic between the person who gives the questionnaire and the person who is doing it and it does sort of like an examiner and examinee relationship, and I think a lot of the time there aren't just expectations put upon both people there, but particularly with regards to assessment and feedback questionnaires, whatever you write has a reflection on one party, so if I write like I'm declaring some sort of distress there, or I feel like the service that they provided isn't adequate, I'm making a comment on one of us and it is very personal, it doesn't feel appropriate for them to be there.

In some ways, when I was filling it out and then it got better, like especially when I had made a significant difference, for a brief moment can be exhilarating.

Theme 4: An opportunity to talk about things important to me

Several participants expressed the desire for a shared dialogue with the health professional and having their support at-hand in case it was needed as part of the process of completing the measures. Some participants were particularly concerned that some questions may trigger distress. Others saw the health professional's presence as enhancing the transparency of the process and then enhancing the shared discussions that could then occur, either whilst they were completing the measures, or immediately after as part of their contact and therapeutic work with the health professional.

We had our session 1st and it came towards the end ... [psychologist] they'll just be quiet in this seat with me and they said 'if you've got any questions', and they just sat with me and just asked me how I was doing ... By staying the room now with me, though, you know focusing on me and just you know things, anything you know ... and that obviously they could see my face as well... and what you know triggered, maybe a question triggered something ... So yeah, it's very supportive... when they saw that you were being triggered by one of the questions.

[Them being there in the room, do you think that that gave them an opportunity to see if things have changed for you?] Of course, absolutely yeah ... You know, you're not just going yes, yes, yes, yes, yes, you know ... they can actually see that you're taking care to do it ... They can see whether you're just ticking the boxes for the sake of ticking the boxes, or whether you're actually taking time to think about things and your responses. So then, you can talk about it as well.

So, I actually filled it out and gave it to her and then she did the scoring, and she was like 'oh I can see that things have been really tough for you lately, for your scores to be this high this is not like you', and then we went in and had a session ... So that showed to me that she actually cares and she actually knows where I am at because that was her response and it was true, things had not been going well, and so she recognised that instantly just from the scoresheet from the DASS 21 which was quite phenomenal.

It's always been part of our ongoing therapy. We just bring it out to just sort of check in, see how I'm feeling, where I'm sitting on those questions, so it's a measuring tool and it's just conversational. And it's more context based, so there's a lot of context. 'So, you say you have been feeling tired for no good reason. What's been happening? Is it the baby? Is it your chronic fatigue? Do you think you're taking on too much?' So, they are prompters if that makes sense. We got prompted to actually check in on where I am at, what's happening, what are the triggers surrounding those feelings?

There is a difference in talking and rambling and you know, talking about what's going on in your life. And then there's another thing filling out that survey and actually, sometimes you know you've got that nought to ten, and sometimes you need more comments underneath to verify or not verify, but explain how you're feeling not just a number. Sometimes you know you need to have more information, but yeah, it's a good indication of you know how you're progressing.

“ Things had not been going well, and so she recognised that instantly just from the scoresheet, from the DASS 21 which was quite phenomenal. ”

4.1. Useful as prompts for further discussion

Participants also spoke about the importance of what happened next with the results of the measures; how they and the health professional used the measures to open up further areas of discussion, and how the results of the measures were used to inform plans for care and support, decisions about treatment options, and ongoing monitoring of progress.

Several participants described how the completed measures and the discussion that followed helped them to feel more understood by the health professional and therefore more engaged and able to work together.

So, I think he understood me better and what was going on in my life, but not necessarily important. Yeah, unless I'd brought that up, I don't think the question would have necessarily – [No, so it's not the questions in the tool you found to be helpful, but it was the discussion after the questions?] Yeah.

She [GP] also, she questions certain aspects of it, and she takes it quite seriously. I mean, it's part of the process ... to get the support that one requires. But she takes the question seriously. She takes the outcomes of the question seriously ... she compares it to the previous occasion or occasions. I will make a comment 'Wow that's higher than previous'. You know something like that, she takes it seriously ... Using it for not just getting to know you better as a bloke ... but also getting to know when to refer on clinically ... and that's why she does it quite frankly. It's so she knows for her it's the next step in the process. It's probably the first step in the process of getting the required support.

Participants also emphasised the value of using the measures over time, as a barometer or benchmark, to gauge progress, plan, motivate them, and support recovery.

[What would you say to new clinicians about the importance of using these surveys or measures?] For me it's a barometer of how the patient is faring in terms of their current level of pain or a trauma etc, and so that's good to know; it gives a benchmark ... It's to see what the recovery process might look like going forward, so when it's repeated to see if the K10 it's actually working, to see whether the K10 is actually assisting with ongoing support, with recovery, improvements in recovery ... It's part of the process.

She does the same thing with my bloods. She checked when I had my blood checked every quarter. She refers to the previous bloods ... You know, for her it's a good measurement, I guess a barometer of where we are now versus where we were. So, I think she uses it in the same way to monitor my blood.

You know to actually see them go back and review, contrast, and compare what has been on the forms to the updated ones, to use that to gauge my progress and my improvement. It felt more than just, you know a piece of paper that they had to take. I definitely felt like they were taking that on board, and I guess tailoring the treatment to that as well.

It will be a sort of progress determiner, you know, on where I will have filled out a K10 pre-medication, then come back in a month or two later to see my GP again. She'll get me to fill out the K10 again and she can determine whether that medication is helping improve my mood. Giving me a bit of stability just based on the from A to B.

I think when you can see that when you do the scores, and you can see the improvements and it's there and you recognise them as little wins in your mental health getting better. And I think for me, I can also go, 'Yeah, so you are getting good scores, now what? What are you doing? What's changed for you to get those good scores? Is it just medication or are you doing other things?' And I know certainly for me at the moment, you know, you read and it says for depression, or for any mental health issues, do more exercise eat more healthily don't drink alcohol, don't smoke and you go - Yeah. Yeah, yeah yeah. Yeah yeah.

One consumer also highlighted that the way they approach completion of the consumer self-assessment could prompt and create more space for the clinician to engage more in conversation.

They can see whether you're just like going, you know, ticking the boxes for the sake of ticking the boxes, or whether you're actually taking time to think about things and your responses. So then, you can talk about it as well.

4.2 Enhancing communication, collaboration, and teamwork across services

Some participants spoke about the value of sharing the outcomes of the measures with the various health professionals and services that provide them with mental health support.

So, this process it's quick, it's efficient. It's necessary, and it works ... I'd say the only room for improvement and there's room for improvement, is that my GP might do the form, then the referring psychologists gets the answer. So, what happens is that there's actually no transparency at a government level or processing level as to what the outcome is. So, my GP, she doesn't know the outcome. As far as the outcome, she says see your psychologist. My GP did the form, but my psychologist knows the answer. That doesn't make any sense ... I just think the sharing of information amongst all the medical people who support you could be better.

I kind of trusted them to share the information ... They were very transparent about it. I think there was even a signing of the document to authorise, you know? But I also kind of liked the idea of my GP and my psychologist collaborating in that way because when I was in the state that I was initially when I was seeking help, it was good to not have to have to chase that up and be that middle person. It definitely cut out the double handling of things.

Conclusions

This research provides a rich description of what works best for consumers and the value of the NOCC measures when used well by clinicians. The results suggest a number of directions for how mental health professionals can use the measures in a positive and productive way when working with people with mental health concerns.

Recommendations

The results of this study identify potential improvements for the use of the consumer-rated measures in mental health services. This has resulted in the following six recommendations for clinicians using the consumer-rated outcome measures.

Recommendation One

Actively engage in a conversation with consumers around the consumer-rated measure and its implications.

By completing the consumer-rated measures, consumers in this study indicated that they felt actively engaged. It gave them a voice in the assessment process.

Recommendation Two

Explain the purpose of the measures and identify the consumer's preferred method for completing.

Given their positive experiences of completing consumer-rated measures, the consumers in this study believe that these should be offered to all consumers. Based on a variety of experiences when completing the measure, they indicated different preferences for when and how they might complete them. Some expressed a desire to complete a measure privately, while others saw advantages to its completion with the clinician. Some consumers spoke about how this impacted their sense of trust and empowerment. The key is to ask each consumer what their preference is.

Recommendation Three

Offer the measures in a way that engenders hope and the opportunity for recovery.

Throughout this study, consumers identified that the way the measures are presented is an opportunity for the clinician to build trust, rapport, and share a sense of hope for the possibility of change in the future. With the knowledge that the clinician is going to routinely offer the measures, it provides a sense that the clinician is working and striving *with* them, to check in and track progress.

Knowing that the measures are not a 'one-off' reinforces the benefits of measuring change over time and gives a purpose to setting goals in their recovery-oriented journey.

Recommendation Four

Discuss the consumer's ratings of the measures with them each time they are completed.

Consumers in this study found that clinicians who engage with curiosity and are interested in the person, help establish a sense of rapport. The completion of the measure, and discussion ensuing from the ratings, provides an opportunity for a much broader and richer discussion.

Exploring the reasons for changes in ratings was found by consumers to be particularly useful.

Recommendation Five

Adopt an approach that encourages the consumer to reflect on their current situation and how it has changed over time.

The consumers in this study identified that the consumer-rated measures can be confronting but gave them an opportunity to reflect and gain perspective of their current situation, and an opportunity to be honest with themselves and others. Consumers indicated that the measures provide an opportunity for both the clinician and the consumer to track progress over time.

Recommendation Six

Encourage consumers to explore the use of the measure for their own self-management and empowerment.

Consumers in this study saw the completion of the consumer-rated measures as an opportunity for personal reflection. It gives the chance to celebrate the good times and gain pride in their achievements, to be pleased when things are 'going the same' or to realise they are 'stuck' or that things are not going well. By encouraging the consumer to "hold the pen" they take a small step in empowering themselves in their recovery journey with the clinician.



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