YES SURVEY

LIVED EXPERIENCE PERSPECTIVES OF COMPLETING THE YOUR EXPERIENCE OF SERVICE (YES) SURVEY

AMHOCN

Lived Experience AUSTRALIA

Table of Contents

Acknowledgements

Report Authors:

- Betty-Jean Dee-Price
- Rosemary Dickson,
- Tim Coombes,
- Lana Earle Bandaralage
- Anna Gould
- Shin Keith
- William Lau
- Paul Milne
- Heather Nowak
- Sharon Lawn

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Background

About the YES Survey

The Your Experience of Service (YES) survey was developed by the National Mental Health Consumer Experiences of Care project and first became available in 2015. The YES survey is designed to gather information by asking people who receive mental health services about their experiences of care. By helping to identify specific areas where quality improvements can be made, the YES survey can support collaboration between mental health services and consumers to build better services. More information about the project is available in the 2013 final report: National Mental Health Consumer Experiences of Care Project: Final Report.

About this Study

The YES survey plays a very important role in improving mental health services because it is one of the few formal ways that people who are in contact with services can provide feedback. For this reason, it is important to know if the YES survey is working well. Prior to this study, little was known about lived experience perspectives of the process of accessing and completing the YES survey. Lived Experience Australia in partnership with the Australian Mental Health Outcomes and Classification Network (AMHOCN) conducted interviews with 12 people with mental health lived experience about their experiences of completing the YES survey.

Aims of the Project

We aimed to hear about experiences on the use of the YES survey from the perspective of people who are recipients of mental health services and are approached by mental health service providers to complete the survey. These experiences will be used by AMHOCN and others to support development of training and best practice methods for mental health workforces within clinical and non-clinical mental health services (Community Managed Organisations (CMO), Primary Health Network (PHN) commissioned services) that are embedding the YES survey within their services. More specifically, we aimed to:

- Seek the views and expertise of mental health service recipients with experience (whether positive, neutral or negative) of completing the YES survey (in either clinical or CMO/PHN services) in order to understand better their views about how the YES Survey is being used in routine mental health care, and its potential impact of their experience of services.
- Understand how feedback from mental health service recipients on the use of the YES survey can inform training for mental health staff, in order to promote wider use of the YES survey and improvements in person-centred service delivery within mental health services.

That is, the project did not seek participants’ views on the YES survey itself or ways that the questions in the measure might be changed but an understanding on how the existing measure could be used more effectively to increase its uptake and support mental health workforce training.

Methods

Study Design

The study was conducted in three phases. As a lived experience-led inquiry, deep planning and design input was sought from the LE community. Although the project researchers are persons with lived experience, a group of lived experience advisors was established as a preliminary phase for the purpose of co-designing the data collection (interview phase).

We were interested in understanding the broad experiences of participants. All experiences of the YES survey were sought; positive, negative and neutral, irrespective of whether the survey was completed or not, and included such things as the processes of being introduced to/offered the survey, access to the survey, perceptions of what happened with their survey feedback, and post-survey follow up.

Project Phases

The investigation used qualitative methods and was conducted across three phases:

Phase 1 involved the recruitment of a co-design group of people with lived experience to discuss, plan and co-design the content for phase 2 interviews. This group included people who had lived experience of being offered the YES survey, offering the survey to others as part of their roles as lived experience peer workers within mental health services, or both.

The co-design group discussion was conducted across three iterative meetings where the group built and refined ideas at each meeting. Discussions were recorded via TEAMS, given members were located across Australia, to ensure their valuable ideas were accurately captured. Meeting transcripts and summaries of content were then provided to the co-design group members after each meeting to check for accuracy, reiterate the discussions to enable any further reflections, and seek their further feedback.

Phase 2 used the on-line meeting platforms TEAMS and ZOOM to conduct interviews with 12 participants using a combination of semi-structured and open questions. Participants were invited to reflect on their experience(s) of answering the YES survey. This involved describing the context (method and delivery) of how the survey came to them as well as their sense of the survey's purpose and impact. Participants were asked to share their thoughts about the survey content, their feelings about answering it, as well as their understanding of the survey process (how their feedback might be used) as well as any results or follow-up they have experienced after answering the YES survey.

Phase 3 involved the co-design group meeting to discuss the preliminary findings from interviews as part of finalising the themes, direct quotes to be included, and recommendations arising from the findings.

PHASE 1

Recruitment of a co-design group to discuss, plan and co-design interview content

PHASE 2

Online interviews, semi-structured and open questions

PHASE 3

Co-design group reviewed findings, themes and recommendations

Ethics

The study was approved the Flinders University Human Research Ethics Committee (No.7051).

Recruitment

Participation in the study for both the co-design group and interviews was advertised via Lived Experience Australia to its national ‘friends’ network. The co-design group was drawn from Lived Experience Australia’s national representative panel, a diverse group of more than 100 current and emerging mental health lived experience advocates. An expression of interest was sought from panel members who identified that they had awareness and experience in the use of the YES Survey. Interviewees were recruited via Lived Experience Australia’s national e-news, with clear criteria that they had experience (either positive or negative) of being offered or completing the YES Survey in the past.

Data collection

The on-line interviews were approximately one hour in length. The interviews were undertaken by a member of the research team who brought a combination of skills and expertise to the data collection process, including lived experience mental health and disability health research expertise.

Data analysis

The research team brought a combination of skills and expertise to the analysis process including backgrounds in disability health research expertise and mental health lived experience, as well as experience in mental health service provision across diverse populations, settings and contexts. The analysis process involved research team members independently reading the interview transcripts and then meeting to discuss their reflections on the data. Tentative themes were then refined via series of email exchanges into a descriptive summary. The investigation, therefore, used an inductive approach (based on the researchers’ interactions with the data) to conduct a thematic analysis of content. Interview transcripts were thematically analysed to identify, interpret, and report on the repeated patterns of meaning arising from the interview data.

The descriptive summary of draft ideas was provided to the co-design group for further reflection, discussion and feedback together with the research team, before finalisation of the themes and recommendations. The co-design group, offered a range of perspectives to the planning of this project such as their own lived experience of being offered (and answering) the YES survey or offering the survey to others as part of a peer worker role. They also brought lengthy experience of participation in systemic advocacy, peer leadership and co-design processes; expertise that further informed the final themes that are identified in this report.

Themes

Emerging from the interviews were multiple themes which we have categorised under the following main headings.

- Opportunity (for voice and agency)
- Delivery (of the survey)
- Change (must be seen)

When participants described negative experiences of the YES survey or raised concerns, they were invited to offer any recommendations they may have for addressing these concerns. These are described further at the end of this report.

Opportunity for voice and agency

The opportunity to voice concerns in order to assist positive change outcomes was the primary motivation for participants to answer the YES survey.

> *"Sometimes in mental health when you don't have such a great experience of services it motivates you to get into a space to help others not have such a journey. As far as recovery that would be one way to shorten it. To help people find that sense of meaning in their lives so I think it could make a bad experience have the reverse effect." (PWLE/ YES Coordinator).*

Some participants indicated insufficient or unsatisfactory pathways or opportunities for providing feedback within services, as part of their everyday interactions with service providers. Some participants completed the survey as part of a "snapshot census" approach within their service or jurisdiction. For this reason, the YES survey was viewed as being a particularly important method for helping to improve service delivery.

> *"My experiences with my services, particularly over the last couple of years, have not been positive and I've gone through Mental Health Complaints Commission and so on and just not have any kind of change come out of that. So, I think it's quite important to kind of keep expressing that you know there are issues that we could really change." (N)*
> *"Staff cross the line around how they treat you and you need to be able to say what happened." (A).*

The study participants considered it important to have the opportunity to provide positive as well as negative feedback.

> *"Yeah, I've been in a number of different psychiatric hospitals and different services and things. And yeah, a lot of times I only fill them out if they were really bad services or really good services. ... So yeah, so in the hope with the bad, I guess was to try and get things better and I guess the hope with the good was to make sure they did it again." (JE)*

The concept of having at least some agency to help inform positive change was a significant theme and was strongly related to the motivation of participants to complete the YES survey.

> *"I'd been in the mental hospital when I was a 19-year-old and then I'd been there as a 40-year-old and not much had changed. So, I was like, wow, I'd like to say something about that". (JO)*
> *"It's either send it off and hope something comes out of it or do nothing." (AL)*
> *"It's about the agency, the control the ability that I can shape my own life and journey and that YES could be one way. The fact that you can feel you have control over some element of your life." (PWLE/ YES Coordinator).*

Results

Participants

A total of 12 participants were interviewed. Once interviews commenced, it became apparent that two of these participants did not meet all of the stated eligibility requirements of the project. These two participants were people with lived experience (PWLE) (one mental health services recipient and one carer) who were working in YES coordination roles at the time of the interviews. Neither had previously answered a YES survey as a service recipient; however, their contributions were considered valuable for providing important context to the findings. The data received from these participants was considered in isolation, and their quotes are included in the report (indicated as 'PWLE/YES Coordinator ').

The study participants were from diverse cultural backgrounds and gender identification. There was a good balance of age from young to older adults and three of the participants identified as being 'disabled'. Five participants described current paid employment in mental health roles, primarily in peer work, and most revealed backgrounds in training in mental health with some currently enrolled in health-based university degrees. All participants made references to their involvement in various, ongoing forms of mental health advisory and advocacy roles.

A note about language:

The mental health space is a rapidly evolving one where every-day practices can sometimes be challenged by the community. Language used in mental health is one area. Participants interviewed in this study raised concerns about the term 'consumer'.

> *"I ***** hate that term (sic consumer). I'm just gonna put it right out there like that. I hate it. I had to use it because it's the way that they use it in the systems. I hate the word recovery as well. I say well-being for myself because it's all been co-opted elsewhere, but I've had to use consumer, I've had to just to with that language. I hate it. Most people I know hate it." (A)*

There were also participants who described themselves as having a disability (mostly non-mental health-related). They used a mixture of language to identify – disability-first language (disability pride) e.g., I am a disabled woman; or person-first language e.g., I am a woman with a disability. For this reason, for the rest of this report we use both types of language.

These interviews provided a rich source of information on a wide variety of issues related to the experience of mental health services, and their delivery. Participants also expressed views on the development of the YES survey and its limitations, co-design in services and their improvement and the need for advocacy to ensure ongoing quality improvement. The analysis and reporting focused on the project aims and are reported here.

The capacity for survey respondents to track and read back over their feedback and to appreciate it within the context of time changes was also highlighted (how their past feedback might compare to their more recent feedback), including the suggestion of an on-line password protected portal system that they could access. This suggests that they wanted more ownership, control and agency in the feedback they provided; and that it was important to them to provide feedback.

Delivery (of the survey)

How participants were introduced to the survey and supported to answer it formed another major theme.

When offered the survey, most participants indicated it was provided to them when they were being discharged from the service (e.g. by the desk clerk/administrative staff prior to them leaving an inpatient unit to return home), and occasionally by a peer worker. Several participants described their dissatisfaction with the YES survey being offered only at this stage in their contact with services; that the timing seemed to be driven by what the service needed rather than what the service recipient needed or preferred.

> *"Like my first interaction with it was when I was about to be discharged, and they were handing me all the discharge paperwork. I was still really acutely unwell. They handed me all the discharge packages. 'Oh and by the way, can you fill this out as well." Like, while I'm here trying to do the Wellness plan for discharge and figure out where my supports are going to be and all that, and it seemed to be an afterthought."(AL)*
>
> *"I'll be honest, I just wanted to say whatever I had to say to go home. I was just missing my wife and children. I was in a different city, and I just wanted to go home, and I think that coloured it. No, I'm not gonna say paranoid, but I was. It was ..Here's what we have to do to tick the boxes to allow you to walk out that door and so let's get it done." (MI)*

One participant's comments suggest that staff perceptions of capability and capacity of the PWLE may be the reason for why the survey is only offered at discharge.

> *"I think the level of stigma amongst mental health staff is quite high. I think they assume because someone's in there with paranoid schizophrenia or delusions of grandeur or whatever, they cannot give feedback. And so, they wait until the person stabilises, they're well enough to go home." (AL)*

Participants described variability from staff around when the survey could be offered. Some described that this survey could only be made available to them at discharge.

> *"And I was never told it was that way. So I was on the belief that I could only use it when I was being discharged. And when I did ask once when I was in there, can I fill one out? They're like, no, it's only for discharge, which I have since learned is not the case." (AL)*

Variation across states and territories in their approach to YES implementation may account for some participants describing inconsistency in whether or not the survey was offered.

> *"Not being directly offered the yes survey is very disempowering. Asking people what their thoughts are verses uhh not. At the end of the day, it's been about empowerment where, where you can give feedback and feel you have a voice." (PWLE/YES Coordinator).*

The window of availability of the YES survey presented a concern for some participants who indicated their preference for it to be consistently available not just at set times of the year (like a census), as determined by services. Participants expressed a preference for a longitudinal continuous collection rather than a census approach.

The experience of whether participants could receive support to complete the survey, (from someone they chose to support them) was another area of inconsistency.

> *"I would be told like I have to fill it out, that my carer couldn't help me because it was my experience." (JE)*

The experience of the above participant contrasted with another who described how the YES survey was successfully completed with the help of a therapist as part of their planned contact with the therapist.

> *"It (sic YES survey) ended up becoming one of the sessions. I can't remember who I did it with. I'm trying to think if it was my care coordinator that I did it with. I feel like it might have been her because she was really good at all that sort of stuff". (RA)*

Those who described positive experiences of completing the survey often indicated the support of peer workers and/or trusted staff. However, the ability to speak safely and openly with whoever was providing the support was raised by participants which is echoed by one of the YES coordinators interviewed.

> *"But I found that when clinicians were doing it, (sic assisting people to answer the survey) people felt very obligated to say what they wanted to hear.*
> *Or they would say 'I don't want to fill it in'." (PWLE/ YES Coordinator).*

Participants who experienced support from trusted peer workers or other staff appeared to have more positive experiences with respect to answering the YES survey. Being listened to, validated and understood were important features of this.

Physical barriers to accessing the YES survey were described by several participants. Participants, with co-occurring conditions such as dyslexia and acquired brain injury, described problems with both reading and comprehending the survey.

> *"Pre brain injury I could (sic answer the YES survey) I've now got a brain injury, and I can't read very well so the surveys aren't very clear. Or when I use a screen reader, they're not screen reader friendly." (JE)*
> *"I think, especially for someone like me who leans on like, you know, who also has a disability. I sort of find that I express myself better when I'm, you know, interacting verbally." (AN)*
> *"You know, it's really hard to, like, fill in a survey with so many words when you've got this condition." (AN)*

Participants described the importance of having support available to access the survey to help mitigate barriers to being offered it and completing it. (AN)

“There definitely needs to be a paid role to help community members access things like these (sic YES survey) from people that know and have experienced the same frustration.” (CI)

> *“I think, especially for someone like me who leans on like, you know, who also has a disability. But I sort of find that I express myself better when I'm, you know, interacting verbally. I would find something like that much more like”. (A)*

The value of support is reflected in a participants’ description of an alternative approach to being handed the survey upon discharge or having it sent to them in an email.

> *“What could be done? I think there’s a couple of things. The first one is a general conversation with the person before the word ‘survey’ is even mentioned. “What fears do you have? How have your perceptions changed since you’ve been here last, that sort of stuff. And just talk people through not just “ok you can go now, so pack up all your stuff – and oh here’s your medicines here’s a survey.” (MI)*

The PWLE/YES coordinators offered special insight into strategies they use to help build trust with PWLE and overcome survey barriers. Their collective experiences of mental health services including involuntarily hospitalisation, being a carer, and peer worker before becoming a YES coordinator offered exceptional insights that the study could not overlook.

> *“I went and sat with people in the waiting area, and we filled out the YES survey and they said it's really bland. It's just awful. You know, I have to come and sit here for the rest, you know, for the next 10 years, And I'm sitting in this awful room and there's nothing. So, I said, OK, put that in and I got and then everyone else said, well, that's how I feel. I said, OK, well, let's write it in. So, then what happened was we got a lot of surveys to say that, and I was able to take that data to management and say this is what people are saying.” (PWLE/YES Coordinator).*

The PWLE/YES coordinator went on to describe the changes to the room, its greatly improved ambiance and now welcoming appearance that included tea and coffee. Both YES co-ordinators described their active collection of feedback from within their own services, and their role entailing responsibility for bringing it together as a collection of responses from multiple service recipients and then taking this information directly to management. Hereto, as earlier mentioned, participants who were supported by a trusted peer worker or other staff member of the service described more positive experiences. This included having a much better opportunity to describe their experiences.

Several participants expressed the view that, if delivered well, the completion of the YES survey could provide an opportunity for personal reflection on their personal journey over time, including what they had or had not received from services and service providers.

Change (must be seen)

The need to see positive change was a major theme that emerged from the interviews. There were also varying levels of dissatisfaction with not hearing back after answering the YES survey.

> *“I wrote so many pages on that first one. Because I found there wasn’t enough room to actually give any kind of reasonable amount of feedback about the service, so I added pages and pages and pages and then after I finished it, I was like, I’m not even going to hear back from this.” (A)*
> *“Boy, I don't think anything I've said has been heard. It seems like feedback gets pushed aside.” (AY)*

As participants described their experiences of not hearing back, some gave recommendations for how feedback post-survey might be better delivered in the future.

> *“If there was like a portal where you can see where your feedback is up to, what's happened with it, so everyone can see the outcomes.” (AY)*

More than half of the participants interviews described not seeing positive changes in service delivery resulting from their survey responses. Many participants expressed scepticism about whether their feedback would lead to improved services, as reflected in the below statements.

> *“I think there's a culture across the board of predominantly ignoring feedback. I don't think the Yes survey really has much of a dent in that whatsoever.” (N)*
> *“Honestly the yes survey, I truly believe has done nothing. I’ve been doing it for 10 years. I truly believe that nothing gets done with it.” (JC)*
> *“To be honest, I think they just use it (sic YES survey) for funding. Like to get funding. They need to show a certain amount of people are using the services to get more funding.” (J)*

Participants highlighted how important their free text qualitative comments provided in the YES survey and their own personal experiences were to services understanding potential areas of improvement. They stressed that this material has to be used to contribute to service improvements and be seen to do so. However, participants indicated concerns that the space required within the YES survey to provide such accounts is insufficient.

> *“It doesn’t get to the nitty gritty, it doesn’t get to your subjective experience.” (AL)*
> *“I found it quite black and white, so it was either a yes or a no. I feel like there was not a lot of room for, like, elaboration.” (AN)*
> *“I'd prefer if they could get like more holistic. If you would be able to answer If you would be able to answer actual questions with actual sentences and stuff.” (JO)*

Conclusion

Participants in this study indicated they valued it as a potentially important tool for positive change in mental health services. This was also evident in the interviews with the two PWLE/YES coordinators. Yet the study revealed participants do not feel heard and do not see change arising from their feedback. They described a range of reasons for this. The people interviewed did more than simply describe the problems; they developed the list of recommendations outlined below. Their enthusiasm in offering potential solutions to improve the experience of completing the YES survey suggests that they valued the underlying premise upon which it was developed and originally intended – to improve services.

Recommendations

Given the themes that were identified, the research team and co-design group identified seven recommendations of equal importance but organised here by theme:

Opportunity (for voice and agency)

- Mental health services should develop a communication strategy that makes clear to the community the existence of the YES survey and the opportunity to inform quality improvement activities within services.
- Ensure that the YES survey is readily available to all service recipients in formats and modes that acknowledge and meet the communication and diversity needs of healthcare recipients.

Delivery (of the survey)

- Services should consider utilising peer or lived experience workers to support both offering and completion of the YES. A welcoming and safe space to complete the survey is made available at all participating sites.
- Training of all staff at YES survey sites so they provide survey respondents with accurate information related to the survey process, including survey collection, reporting and quality improvement activities.
- Services proactively address barriers to survey participation by ensuring all persons are offered the survey, and that support is given to those who may have difficulty accessing it due to disability and other conditions. This may involve offering mental health care recipients one on one support to answer the survey.
- The ability to access the survey at any time should be available, not just within specific service-determined census periods, and at discharge from a service setting.

Change (must be seen)

- Services to establish a feedback process that allows survey respondents to know how their information has been heard, analysed and translated to service quality improvements e.g., “You said” “We did” poster listing service changes resulting from YES feedback.

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