



**Exploring the potential use of patient and public involvement to strengthen Indonesian mental health care for people with psychosis: A qualitative exploration of the views of service users and carers.**

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4 **Exploring the potential use of patient and public involvement to strengthen Indonesian**  
5 **mental health care for people with psychosis: A qualitative exploration of the views of**  
6 **service users and carers.**  
7

8 **Abstract**  
9

10 Background: Patient and public involvement (PPI) has the potential to strengthen mental health  
11 systems in Indonesia and improve care for people living with psychosis. Current evidence from  
12 other parts of the world demonstrates the need to understand the contexts in which PPI is to be  
13 enacted to ensure optimal implementation.  
14

15 Objective: To understand service users' and carers' views on the current use and potential  
16 applicability of PPI within Indonesian mental health services.  
17

18 Design: Qualitative study incorporating focus groups analyzed using thematic analysis.  
19

20 Setting and participants: Participants included 22 service users and 21 carers recruited from two  
21 study sites (Jakarta and Bogor). All participants had experience of psychosis either as a service  
22 user or carer.  
23

24 Results: Despite the value attributed to PPI in relation to improving services and promoting  
25 recovery, current use of such activities in Indonesian mental health services was limited.  
26 Participants expressed a desire for greater levels of involvement and more holistic care but felt  
27 community organisations were best placed to deliver this because PPI was considered more  
28 congruent with the ethos of third sector organisations. Additional barriers to PPI included stigma  
29 and low levels of mental health literacy.  
30

31 Discussion and conclusion: Participants felt that there was potential value in the future use of  
32 PPI within Indonesian mental health services with careful consideration of individual contexts.  
33 Future aspirations of involvement enactment should ensure a central design and delivery role  
34 for third sector organisations. Facilitators to global collaborative research in the context of the  
35 current study are also discussed.  
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38 **Key words:** patient and public involvement, mental health, health services, Indonesia, United  
39 Kingdom, qualitative research, shared decision making.  
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## 1. BACKGROUND

Patient and Public Involvement (PPI) in a mental health context is an umbrella terms that encompasses a range of activities including service user movements to influence politics and change health services, knowledge generated by people living with a mental health diagnosis and the involvement of patients in the design and delivery of care<sup>1-4</sup>. Such approaches derive from a position that traditionally research and clinical decision making has been limited to the realm of intellectual and health institutions and the people that work in them to the detriment of other forms of knowledge<sup>5</sup>. Advocates of this position assert that this has led to health services which at one end of the spectrum are not providing services that adequately meet individual need<sup>6,7</sup> and at the other are openly discriminating against the people they treat<sup>8</sup>. For example the service user movement in the UK 'refers to the work of individuals who advocate for their personal and collective rights within the context of discrimination faced as a result of having experienced mental health difficulties and/or being diagnosed as having a mental illness'<sup>3</sup>.

There is a growing body of evidence for the benefits of involving service users and carers in the design and delivery of mental health services at both a systems and individual level. PPI has been shown to change services for the better<sup>9</sup> through enhanced performance<sup>10,11</sup>, increased accountability<sup>12</sup> and enhanced person centered care<sup>13,14</sup>. At an individual level, reductions in symptom severity, positive impacts on personal recovery, individual rights, mental health literacy, confidence, hope and empowerment are all associated with increased involvement in mental health services<sup>14,15</sup>. Such evidence has contributed to an increased emphasis on participatory approaches in mental health services internationally<sup>16</sup> and these principles becoming legal standards for medical care in some parts of the world<sup>17,18</sup>.

Despite the ubiquity of involvement rhetoric within policy and practice ideologies across the world, current evidence suggests implementation remains far from optimal and service user and carer isolation and dissatisfaction persist<sup>10,19-24</sup>. In a recent commentary, it was argued that true collaboration between people with mental health diagnoses and researchers, policy makers and health professionals cannot happen in environments which continue to perpetuate hierarchies and power imbalances albeit in a less transparent form<sup>25</sup>. Often such imbalances are sustained by macro level factors such as the legacy of prior mental health policy and historical practice, legal frameworks and organizational culture often not targeted or considered by PPI interventions<sup>20,26</sup>. Such findings have led to calls for critical examinations of such entrenched power imbalances and contexts for implementation and for PPI interventions to address these contextual factors to enable true collaboration to be realized in practice. Additional barriers include limited opportunities for involvement<sup>10</sup>, diverse definitions of involvement, inadequate information provision<sup>21</sup>, mental health stigma<sup>27</sup> and existing practices and cultures within health services<sup>10</sup>. Such implementation challenges are underexplored within Low and Middle Income Countries (LMICs) despite the potential applicability of such approaches to improve mental health care<sup>11,28</sup> and the likelihood of unique challenges to meaningful implementation in these contexts<sup>19</sup>. For example, the Bali Declaration (2018) written by people with psychosocial disabilities and cross disability supporters from 21 countries in the Asia Pacific region confirmed the relevance of inclusion to change services whilst concomitantly reaffirming the systematic and pervasive violation of people's human rights in these countries by mental health services<sup>29</sup>.

In Indonesia, as in other LMICs, PPI is an emerging concept, which has not been widely adopted or explored<sup>19</sup>. A recent Human Rights Watch investigation into the treatment of people with psychosis revealed significant human rights violations in Indonesia, including arbitrary and prolonged hospital detention, involuntary treatment, and tens of thousands of people being illegally chained up ('pasung') in unsanitary conditions, both in the community and in hospital

1 settings<sup>30</sup>. Such violations persist despite improvement to mental health care in Indonesia since  
2 the provision of basic community mental health care<sup>31</sup>, improvements to human rights generally  
3 following the establishment of the National Commission on Human Rights in 1993 and recent  
4 changes to international covenants and domestic law which now provide an adequate legal  
5 framework for human rights protections<sup>32</sup>.

6  
7 Mental health is now a national priority in Indonesia and clinicians are starting to develop  
8 community based mental health services to support people living with psychosis. This emerging  
9 service infrastructure and sustained commitment towards improving the reach and efficiency of  
10 mental health services presents a unique opportunity for PPI to shape and strengthen these  
11 emerging systems and ensure that they are designed around the needs and preferences of the  
12 people they aim to serve or to introduce alternative forms of service provision (e.g. third sector  
13 organizations)<sup>33</sup>. A recent systematic review drew attention to the fact that the emphasis of  
14 existing evidence is on clinical practice and professional views and identified a need for in-depth  
15 qualitative research with patients to understanding the meaning of mental health care for those  
16 that use services in order for effective interventions to be developed<sup>34</sup>. This study therefore  
17 aimed to understand service users' and carers' views on the current use and potential  
18 applicability of patient and public involvement activities within Indonesian mental health  
19 services.  
20

## 21 **1.1 Background to the collaboration**

22  
23  
24 The proposal for the study was generated at a research capacity building and priority setting  
25 event in Indonesia in August 2016 funded by the British Council. A further visit to Indonesia to  
26 develop the proposal with local collaborators was funded by the ESRC Impact Acceleration  
27 Account in November 2016. Two PPI consultation events were conducted during this trip with  
28 people with psychosis and their carers to inform the proposed study design and delivery.  
29

## 30 **2. METHODS**

31  
32 A qualitative study was undertaken utilising focus group interviews. The choice of data collection  
33 method was informed by the study PPI advisory group. The PPI advisory group consisted of 12  
34 people who either had lived experience of psychosis or cared for someone with a diagnosis of  
35 psychosis recruited through a partner Non-Governmental Organisation (NGO). The advisory  
36 group was established at the initiation of the wider project<sup>33</sup> and consulted on all project  
37 components. The manuscript has been prepared using the Consolidated Guidelines for the  
38 Reporting of Qualitative Data<sup>35</sup>.  
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40  
41 The study formed part of a larger development award exploring the potential of involving  
42 patients, carers and communities to strengthen mental health systems in Indonesia<sup>33</sup>. This four  
43 phase mixed method study aimed to develop a culturally appropriate framework for use in  
44 Jakarta and Bogor, Indonesia to strengthen local mental health systems. Phase 1 comprised of  
45 a systematic review to explore the involvement of patients, carers and communities in mental  
46 health services across South East Asia<sup>36</sup>. Phase 2 surveyed all mental health professionals in  
47 Jakarta and Bogor to identify the important people, sources of collaboration and evidence  
48 currently used in decision making within local health services and to explore potential  
49 opportunities for involvement within the mental health system. Phase 3 explored the potential  
50 application of service user and carer involvement in mental health services from the  
51 perspectives of service users, carers and national key stakeholders using qualitative  
52 methodology. Finally, phase 4 used evidence from phases 1-3 to inform co-production  
53 workshops to agree priorities for a framework for use in Indonesia. The resultant framework will  
54 be used to apply for further funding to evaluate its clinical and cost-effectiveness in Indonesia.  
55 This manuscript reports on the qualitative focus group discussions with patients and carers only.  
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1 A film with more information on the study can be found here:

2 <https://www.youtube.com/watch?v=aYdX0FPvtOY&t=2s>

### 3 4 **2.1 Participants and recruitment**

5  
6 To be eligible for inclusion in the study, participants had to either have lived experience of  
7 psychosis or have experience of caring for someone with psychosis. Additionally, they had to be  
8 aged 18 or over and have the capacity to consent to take part in a focus group discussion.  
9

10 Participants were invited to take part through the voluntary and community groups they attended  
11 (see below for further information). Advertisements were displayed in community group venues  
12 for a two week period. Interested parties contacted a member of the research team to express  
13 interest in the study and have any questions they had about the study answered. When  
14 sufficient levels of interest were obtained, a time and date for the meeting was agreed and  
15 potential participants were notified. Participants were provided with an information sheet and  
16 consent form in Bahasa Indonesian and given the opportunity to ask again questions prior to the  
17 commencement of focus groups. All participants gave written, informed consent prior to the  
18 group starting.  
19

20  
21 A convenience sample of 43 participants consented to take part in focus groups in three  
22 community organisations (two in Jakarta and one in Bogor). Study sites were selected in  
23 relation to differing geographical, economic and urban-rural contexts, and variety in the standard  
24 and development of mental health systems<sup>33</sup>. Attempts were made to include a range of  
25 participants from both rural and urban areas. Table 1 provides more information on included  
26 study participants. More details on host community organisations can be found below:  
27

- 28 • FG1 - Jakarta: a non-government organization whose activities focussed on delivering  
29 information and advocacy to patients and carers about the rights of mental health  
30 consumers. Participants had significant experience of mental health activism,  
31 involvement in health services and involvement in community organisations.
- 32 • FG2 - Jakarta: participants were in receipt of services in an urban area but had much  
33 more limited experiences of mental health activism. Participants were involved in some  
34 community organisations.
- 35 • FG3 - Bogor: participants lived in a remote area where access to mental health services  
36 was much more challenging and experience of involvement in health services was  
37 minimal. Participants were involved in some community organisations.  
38

39  
40 In line with advice from the study advisory group made up of patients and carers, mixed focus  
41 groups (users and carers/gender) were held in each location.  
42

### 43 **2.2 Data collection**

44  
45 All data was collected by Indonesian researchers supported and supervised remotely and  
46 through face-to-face meetings with UK and Indonesian study leads. Focus group discussions  
47 were facilitated by HS (a mental health nurse academic) in collaboration with BO (a carer  
48 researcher) and BK (a mental health nurse academic). An additional observer was present to  
49 support the digital audio-recording but did not participate in the group discussions. All focus  
50 groups were held in accessible community locations in Jakarta and Bogor. Focus groups started  
51 by asking people about their understanding of involvement in mental health services generally  
52 before focusing on the current and potential use of patient and public involvement in Indonesian  
53 mental health services and the exploration of barriers and facilitators to its implementation. The  
54 focus group schedule was developed and refined amongst authors and translated into Bahasa  
55 Indonesian (See Figure 1 for example questions).  
56  
57  
58  
59  
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1 Focus groups were undertaken between May and September 2018, and lasted between 60 and  
2 90 minutes. Groups were conducted in Bahasa Indonesian, digitally recorded and transcribed  
3 verbatim by an employee of the University of Indonesia before being translated into English for  
4 the purposes of analysis. Transcripts were anonymised at the point of transcription. In order to  
5 ensure the validity of translations, 5% of transcripts were back translated from English to  
6 Bahasa and compared to the originals in order to identify any discrepancies in meaning in line  
7 with guidelines for the undertaking of qualitative research <sup>37</sup>.  
8  
9

## 10 **2.3 Data analysis**

11  
12 Transcripts were analyzed using inductive thematic analysis which involves six phases of  
13 coding and theme development <sup>38</sup>. The process of analysis was underpinned by social  
14 constructionism which recognizes the complexities of individual experience and the importance  
15 of the wider context and focuses on understanding the semantic meaning attributed to people's  
16 experiences <sup>39</sup>.  
17

18  
19 Transcripts were first read a number of times to ensure immersion in the data. HS, HB and KJ  
20 then independently coded all three transcripts before meeting via Skype to agree a final set of  
21 codes. During this meeting, codes were organised in an iterative process which involved the  
22 removal of duplicate codes and the amalgamation of similar or related themes. Researchers  
23 also discussed any discrepancy in coding and agreed final code allocation. Codes were then  
24 organised into potential overarching themes which were considered representative of the  
25 dataset. This framework was shared with the wider study team (other co-authors) for further  
26 refinement before agreement was reached that the identified themes fully reflected the data  
27 from all three focus groups. The final stage of the analysis was writing the manuscript which  
28 involved providing thick descriptions of identified themes and selecting quotes from the raw data  
29 to illustrate interpretations. Quotes are marked with the focus group number along with some  
30 information about the group participating in the focus group.  
31

32 Preliminary analyses of the data were presented to the PPI advisory group in November 2018 to  
33 ensure any interpretations remained grounded in the lived experience of users and carers in  
34 Indonesia and their comments fed in to the analysis process through the development and  
35 interpretation of data, the allocation of codes and theme development.  
36

## 37 **3. RESULTS**

38  
39 Three themes were interpreted from the data which were considered to provide a rich  
40 understanding of the potential applicability of patient and public involvement activities in  
41 Indonesian mental health services: (1) the relevance and salience of patient and public  
42 involvement in Indonesian mental health services, (2) perceived benefits and negative  
43 consequences of PPI, and (3) implementation challenges. C denotes carer participants and SU  
44 denotes service user participants.  
45

### 46 **3.1 *The relevance and salience of patient and public involvement in Indonesian 47 mental health services***

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49  
50 Of the three groups, the NGO for people with schizophrenia and their families (FG1)  
51 demonstrated the most detailed awareness of and expectations for involvement in Indonesian  
52 mental health services. The concept had less salience for the other two groups initially. This  
53 appeared to relate to the former having more direct experience of being involved in mental  
54 health services locally and nationally and of mental health activism. Participants felt that  
55 involvement was often equally as relevant at a community level (i.e. general public kaders -  
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1 trained volunteer workers chosen by and from communities to support services at community  
2 health posts and local governments) in addition to at an individual level (i.e. service users and  
3 carers).

4  
5 *PPI in formal health services*

6  
7 Despite a general desire for PPI in mental health services, there were limited current  
8 opportunities. Examples of PPI identified in health services were mostly instigated by patients or  
9 carers themselves and represented superficial levels of involvement, such as the choice of  
10 recreational activities or one way provision of information. This limited involvement reflects a  
11 potential failure on the part of mental health services to successfully implement article 19 -  
12 Living independently and being included in the community - of the United Nation's Convention  
13 on the Rights of People with Disabilities (UN) in Indonesian mental health services.  
14

15 *Facilitator: Were you asked what kind of therapy do you want by the physicians*  
16 *or nurses?*

17 *C12: Nope. The medication given based on the diagnosis... like haloperidol.*  
18 *They never offer others. Female, 53 years, mother.*

19  
20 ***Focus group 3/ in urban community service***

21  
22 *C2: In conclusion, I think mental health care services have not engaged the*  
23 *community] [sufficiently] yet... in the treatment plans or the support needed. It*  
24 *is more like we [have] got to be the one who is proactive and solve these*  
25 *problems with our own hands. Male, 45 years, sibling*

26  
27 ***Focus group 1/ in support group***

28 Most participants expressed a desire for greater involvement in the design and delivery of  
29 mental health care and for health services to take some responsibility for this.  
30

31 *Facilitator: how far..... or what kind of involvement/engagement that you*  
32 *expect?*

33 *C11: everything, from wake up until the patient sleep at night. Families want to*  
34 *be involved. We need to be asked what patient's needs and wants are. Female,*  
35 *32 years, sibling*

36  
37 ***Focus group 2/ in rural community services***

38  
39 *SU 5: I want to be engaged in social events like psychiatric education for the*  
40 *public, for example like a campaign to fight 'pasung' (physical restraints to a*  
41 *psychiatric patients in Indonesia). As a person with psychiatric disability, I want*  
42 *to share my experience with people in isolated areas with a lack of information*  
43 *about mental illness. Male, 30 years, 5 years duration of illness*

44  
45 ***Focus group 1/ in support group***

46 Some participants described how previous attempts to feedback to services about their  
47 experiences had been met with punitive responses from health professionals. For examples,  
48 complaints were interpreted as a relapse in their condition by health professionals and patients  
49 were secluded or had their medication increased as a result. Others described how involvement  
50 activity did not always bring about desired changes. Such experiences impacted on  
51 expectations and desire for future involvement in mental health services.  
52

53 *SU7: When I became aggressive, they will restrain me. When I complain, the*  
54 *doctor will add the dose. [] If we (the patients) talk too much, the doctors and*  
55  
56  
57  
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59  
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1 *nurses will take it as a relapse, so we are confused and choose to be silent.*

2 *Female, 46 years, 23 years duration of illness*

3 ***Focus group 1/ in support group***

4  
5 Besides information delivery, other involvement activities identified by participants included  
6 inviting service users and carers to deliver recreational classes; including service users and  
7 carers as committee members for event organization, and engaging carers as mental health  
8 kaders for basic care and health supervision in the community.  
9

10 *SU4: At that hospital, I was invited twice by the Public Health Office for a*  
11 *gathering that was facilitated by the hospital for the patient's family. On Bipolar*  
12 *Day, as patients, we were also invited to share our experience and involved at a*  
13 *committee, for example to be a Master of Ceremony. The hospital held a*  
14 *Seminar, Sharing Tips and Tricks Session, once a month for patients. Male, 40*  
15 *years, 10 years duration of illness*

16 ***Focus group 1/ in support group***

17  
18  
19 Most service users and carers; however, felt that involvement in these activities was relatively  
20 superficial with limited opportunities to express ideas and decide on preferred actions.  
21

22 *PPI in third sector organisations*

23  
24 While few participants were satisfied with current levels of involvement in formal health services,  
25 participants were very positive about their involvement in community organisations and the  
26 support they received from these groups more generally. Reasons for this satisfaction related to  
27 there being more opportunities to talk to and share their experiences in a safe environment with  
28 people that understood what they were going through. Relationships with people working in  
29 community organisations were also considered to be improved because of reduced power  
30 imbalances and people in community groups being more approachable. Some participants  
31 directly compared the support they received from formal health services to that received from  
32 community organisations and identified a clear preference for the latter given their ability to  
33 incorporate valued activities into care and not adopting a singular focus on medication provision.  
34

35  
36 *C4: Before I joined with this organization, I could not believe that my son was ill.*  
37 *I searched for the best psychiatrist to help my child. Finally, I found a hospital*  
38 *and I went there while I cried and hoped that the doctor could calm me down...*  
39 *by helping my child. But the doctor didn't let me know of what had happened to*  
40 *my child, and he said "the point is, your child is like this" the doctor said as he*  
41 *raised his index finger in front of his forehead as a symbol for a lunatic person.*  
42 *My heart was so broken, I could do anything but silent, and after he prescribed*  
43 *the medication I told my husband that I will never ever going back to that*  
44 *hospital or meet that doctor anymore. My family was not very helpful either...*  
45 *Finally, I met Doctor X. She informed me about this organization, so I joined.*  
46 *This is the right place for my child and me. The leader told me about my child's*  
47 *condition and I don't feel lonely anymore. When the members gathered, I feel*  
48 *so happy like I was before [knowing my child was ill] Female, 61 years, mother*  
49

50 *SU7: This community is not boring like hospitals. I get so many new friends that*  
51 *I can have conversations with, the leader is also care about me, when I get*  
52 *bored he will ask me to draw. Meanwhile, in hospital, all I have to do is just*  
53 *taking the medicine, I have to wake up early in the morning... just that. I know it*  
54 *was for discipline but for me it was boring. Female, 46 years, 23 years duration*  
55 *of illness*  
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## Focus group 1/ in support group

### 3.2 Perceived benefits and negative consequences of PPI

Participants acknowledged a number of benefits of PPI including sharing burden, sharing skills and experiences, improving confidence, and combating stigma. Most of these positive recounted experiences related to participants' involvement in community organizations.

*SU5: This organization is very helpful to recover and getting my confidence back. I've got so many friends here [voluntary organization]. Once, the doctor asked me to be a secretary of this organization. This makes me to believe that I deserve such thing. Male, 30 years, 5 years duration of illness*

*SU1: An organization like this is very helpful for us. The first time my doctor diagnosed me with this illness, I felt so lonely. My friends left me. But when I joined this community, I've got new friends who are dealing with the same problems as mine so we can share information. My other friends maybe will never understand about my feeling; some even have humiliated me. Male, 32 years, 10 years duration of illness*

#### Focus group 1/ in support group

Other benefits related to the role of voluntary kaders, one carer below describes how this experience not only increased her own knowledge about mental health, but also helped her neighbors to access services.

*Facilitator: In these 2 months being a kader, what is advantage that you've got?*  
*C18: My knowledge increases, and I know what I have to do. I learned some techniques, such as deep breathing to overcome my stress, how to eliminate nervousness, relieve agitation. If I fear of something, I could apply them to calm me down. Female, 42 years, mother*

*Facilitator: Is there any advantage to your environment or society?*

*C18: Thank God, I could persuade my neighbor to visit mental health service if they had problems. If my neighbor has any problem, they could talk to me. Female, 42 years, mother*

#### Focus group 3 in urban community service

Service users and carers who had been involved in PPI activities felt strongly that this experience had been important for their recovery as it gave them a sense of purpose and helped to reintegrate them back into the community. Carers; however, felt strongly that PPI should not overburden family members. Whilst seeing the value of involvement in mental health services, they did not feel they should solely be responsible for care and felt that some responsibility should still rest with the Government and wider community to adhere to the laws related the rights of people with mental illness. They also reported wanting support themselves from health services to support them in their care giver roles.

*C2: I want the negative effects (i.e. in caregiving) such as feeling burdened and crisis... to be addressed by health services [] So, do not let health services have the intention to help, but we as a family become fettered. Like, like they release the chains of people with mental illness, but after that, the family becomes chained. Male, 45 years, sibling*

*C5: We want to provide support, but the government should also help so that the responsibility is not [just] in our hands. We want the government to be involved*

1 too. Moreover, there are already laws that regulate the rights of people with  
 2 mental illnesses. Female, 59 years, sibling  
 3 **Focus group 1/ in support group**

### 6 3.3 Factors affecting the future implementation of PPI in Indonesian mental 7 health services

#### 9 *Desire for PPI activities*

11 Despite the aforementioned shared desire for PPI, participants described how people might be  
 12 unable or unwilling to engage in involvement activities for a range of reasons. These included a  
 13 lack of understanding of mental health and the benefits of PPI, a lack of resources to access  
 14 services and already being burdened by long-term caregiving duties.

16 *C5: They are the community in our neighborhood. Sometimes even the family  
 17 do not know what to do, where to go, they are not in that level of knowing this.  
 18 In the term of engagement, we expect that they are well educated enough so in  
 19 case they see something happens about this mental illness, they won't be  
 20 confused again, because the patients need to be helped as soon as possible.*

21 *Female, 59 years, sibling*

22 **Focus group 1/ in support group**

24 Participants felt that service users, carers and community members may also be hesitant to  
 25 engage in involvement activities because of the stigma associated with mental illness. There  
 26 was a perception that in order to facilitate engagement from patients and carers, involvement  
 27 activities should be offered to people who were distanced from their locality to avoid identifying  
 28 them as someone with mental illness within their own community. In order to combat some of  
 29 these barriers, participants emphasized the importance of offering a range of involvement  
 30 activities so individual engagement could fit with personal circumstances including their interests  
 31 and competencies. Community organisations were considered best placed to offer such  
 32 activities.

34 *C1: I live in a residence. In my experience, when my son relapsed, and not all  
 35 my neighbours know that my son was ill, some of them are insulting, humiliating  
 36 us. Male, 67 years, father*

37 **Focus group 1/ in support group**

39 *SU 16: I will join if it is in here, but I won't do in my neighborhood. Because I  
 40 don't really know them yet. People sometimes underestimate people with  
 41 mental illness. "Look, there is a crazy person" Male, 34 years, 10.5 duration of  
 42 illness*

43 *Facilitator: How about the others? Would you join in neighborhood events?*

44 *SU17: No, we won't Male, 30 years, 10 years duration of illness*

45 *C16: I am not keen to let my daughter ... [to be involved in activities in our  
 46 neighborhood] ... I'm afraid people will think wrong about her. Female, 46  
 47 years, mother*

48 **Focus group 3/ in urban community service**

#### 50 *Professional capacity to implement PPI*

52 Participants felt that professionals in formal health services may not be able to enact PPI  
 53 because of a perceived lack of relevance to their roles, fear it would exacerbate workload, poor  
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1 communication skills and a clinical focus generally on medication. Paternalism within health  
2 services was also considered likely to further inhibit PPI.

3  
4 *C4: One service user told us that the nurses just gave her medicine, maybe it  
5 happened because they have limited time and energy. Female, 61 years,  
6 mother*

7 **Focus group 1/ in support group**

8  
9 *C5: We feel that health workers are often too confident and feel too much that  
10 they know everything. This makes their attention to us is minimal because they  
11 already feel their service is good enough... with the services provided daily. The  
12 patients will not going to ask nurses for a chat because they are afraid of  
13 disturbing the nurses... Female, 59 years, sibling*

14 **Focus group 1/ in support group**

15  
16 Participants felt that health professionals needed training to improve their skills in delivering  
17 information, communicating with service users and carers and providing opportunities for  
18 service users and carers to be involved in decisions about care.

19  
20  
21 *C8: According to what I have seen in my brother, something that needs to be  
22 improved is that communication from the professionals. Let's say he is a service  
23 user but sometimes they talk rude... sometimes they talk nice but hurtful...that's  
24 it... Female, 24 years, grandson*

25 *C9:[] The communication to carers should be also improved. Because the one  
26 who knows about the service users' condition in the house is their family. Ask  
27 the family as well. Female, 43 years, sibling*

28 **Focus group 2/ in rural community service**

29  
30 *Lack of organisational readiness to implement PPI*

31  
32 Participants felt that conditions in formal health services were not optimal for PPI. Reasons for  
33 this included poor co-ordination between services and complicated bureaucracy relating to  
34 involving service users and carers within services. Nationally, participants described inadequate  
35 distribution of financial and personnel resources, the pervasiveness of stigma towards mental  
36 illness and the low political salience of mental health services at a national level when compared  
37 to physical illnesses.

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39  
40 *C5: The bureaucracy must be simplified. Currently, if we want to do something,  
41 we are often complicated and asked to contact one person to another. It takes  
42 quite a lot of time and energy then we don't want to do it. Female, 59 years,  
43 sibling*

44  
45 *C5: In addition, mental health is not as popular as other diseases such as heart  
46 disease, HIV, etc., so that health workers may not bother. Therefore, all this  
47 time I think mental health services are still very lacking. Female, 59 years,  
48 sibling*

49 **Focus group 1/ in support group**

#### 50 51 **4. DISCUSSION**

52  
53 This study aimed to develop current understanding of the potential use of PPI to strengthen  
54 Indonesian mental health services for people with psychosis. A thematic analysis of three focus  
55 groups conducted with 22 service users and 21 carers identified the limited use but potential  
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1 value of such activities, the significant role of community organisations in relation to realizing  
2 PPI and driving change in Indonesia as well as a number of potential implementation  
3 challenges.

4  
5 In line with research from other parts of the world, participants expressed a desire for greater  
6 levels of involvement in mental health services <sup>6,10,21</sup>. However, in the current study carers  
7 coalesced in their concerns that any increased emphasis on involvement in Indonesia should  
8 not over-burden carers or detract from Governmental or societal responsibility for the care of  
9 people with mental illness. This may be reflective of an ongoing lack of mental health service  
10 provision in Indonesia more generally <sup>32</sup> despite improvements to mental health care since the  
11 mandatory provision of basic community mental health care, improvements to human rights  
12 generally in Indonesia following the establishment of the National Commission on Human Rights  
13 in 1993 and recent changes to international covenants and domestic law which now provide an  
14 legal framework for human rights protections <sup>32</sup>. Whilst involvement appears to hold potential  
15 value to Indonesian mental health services, it is unlikely to be a panacea without consideration  
16 being given to these wider contextual factors further highlighted by study participants through  
17 concerns about lack of organizational readiness to implement PPI. The health needs of carers  
18 themselves should also be addressed in addition to improving care for people with mental  
19 illnesses <sup>21,40</sup>.

20  
21  
22 Participants in FG1 had significantly more experience of mental health activism, involvement in  
23 health services and providing care for people with psychosis. As such, the concept of PPI had  
24 greater salience to their current activities and mental health care compared to the other two  
25 groups. Participants in all three groups however described how involvement activity was more  
26 congruent with the ethos and function of third sector organisations because of the increased  
27 time people had to spend with them and their approachability. Some participants directly  
28 compared care from health services and these organisations and stated a preference for the  
29 latter because activities extended beyond medication prescription to include valued activities  
30 (such as art and creative pursuits) in line with patients in the Global North <sup>7,41</sup>. Any attempts to  
31 implement PPI in Indonesian mental health services should do so in close partnership with such  
32 organisations to draw on their expertise of working collaboratively with patients and carers and  
33 providing care which more adequately addresses individual needs. Service user organisations  
34 have been key drivers in the success of PPI and instigating change in other countries including  
35 LMICs and as such should be considered fundamental to PPI implementation in Indonesia <sup>3,42</sup>.

36  
37  
38 Another finding of interest was a conceptualization of PPI which extended beyond participation  
39 at an individual level reflecting a more collectivist culture <sup>36</sup>. Participants felt that the care of  
40 people with mental illness was not solely the responsibility of service users, professionals and  
41 carers, but also implicated the wider community including public figures, local government,  
42 police and neighbours. The mental health kader scheme, in particular, whereby members of  
43 local communities are trained to provide basic mental healthcare was viewed positively in terms  
44 of meeting the needs of service users and carers, as well as improving community relations  
45 which supports wider literature on the use of lay workforces in this South-East Asian region <sup>43</sup>.  
46 Such findings contradict the implementation of PPI in Western contexts which focus on person-  
47 centered models. Tensions between the ethos of personalization associated with person-  
48 centred care and the collective efficacy characterizing mental health activism has been  
49 identified previously in the UK as a potential reason for the failure of involvement initiatives  
50 within mental health care <sup>26</sup> and will require careful consideration in Indonesian contexts.

51  
52  
53 Participants reported similar barriers to PPI as those in other parts of the world. These included  
54 lack of knowledge about mental health, fluctuating health status, stigma, paternalism, resource  
55 limitations, professional resistance, a need for parity of esteem between mental and physical  
56 health conditions, and lack of understanding about the benefits of involvement <sup>44 10 19,45</sup>. This  
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1 highlights the need for the development of national resources and guidance for PPI in Indonesia  
2 in line with that developed by INVOLVE in the UK to address some of these identified  
3 challenges <sup>46</sup>. There were a number of barriers that were of increased salience to participants in  
4 the current study including low levels of mental health awareness and high levels of stigma.  
5 These barriers identified previously in Indonesia have been shown significantly impede access  
6 to care and recovery for people with mental illness <sup>30</sup>. Given the importance attributed to  
7 community organizations and NGOs by participants in the current study, attention should be  
8 focused on developing creative ways to support and engage third sector organisations to  
9 promote mental health literacy, promote social inclusion and reduce stigma in Indonesia (e.g.  
10 support the development of national NGO networks and consider making NGOs an arm of  
11 psychiatry) in a way that does not diminish their unique position and strengths. Recent evidence  
12 suggests that one way to do this is through public engagement events which combine education  
13 and arts-based activities which promote interpersonal contact between people with mental  
14 health problems and the public <sup>47,48</sup>. A recent evaluation of a mental health festival in Indonesia  
15 further demonstrates the potential utility of such approaches within Indonesian contexts <sup>49</sup>.

### 17 *Strengths and limitations*

19 Through its combination of focus groups and in-depth qualitative analysis, this study has  
20 developed current understanding of the potential use of PPI within Indonesian mental health  
21 services. The results can contribute to the development of a culturally appropriate and needs-  
22 based PPI programme for future use in Indonesia. The study focussed solely on the views of  
23 service users and carers and future research should explore the views of health professionals,  
24 policy makers and government officials to further enhance the use of PPI in Indonesia. Future  
25 research should also consider the use of individual interviews with service users and carers to  
26 explore some of the issues identified in the current manuscript in more depth.

29 The focus group discussions and qualitative analysis were enhanced through the inclusion of a  
30 carer-researcher who co-facilitated focus groups and contributed to the analysis of transcripts.  
31 Emergent codes and thematic frameworks were presented to an advisory group of patients and  
32 carers whose comments informed the development of final themes and ensured the analysis  
33 was grounded in the lived experience of mental health services in Indonesia. All data was  
34 collected and analysed by Indonesian researchers with UK collaborators providing qualitative  
35 supervision and guidance to support the analytical process.

37 All participants were from the Java region of Indonesia and self-selected themselves for  
38 inclusion in the study having all received some form of input from mental health services. Data  
39 may therefore not be generalizable to other mental health stakeholders such as those who have  
40 not received any form of mental health service.

### 42 *Reflections on global partnership working*

44 This study represents an on-going global collaboration between Indonesian and UK mental  
45 health academics. This study built on previous collaborations in the form of capacity building  
46 activities and development work and this study enabled these existing relationships to be  
47 strengthened. These relationships were of paramount importance to the success of the study  
48 and enabled the project to overcome a number of challenges including contractual delays and  
49 lengthy financial processes which significantly impeded progress. Additionally, natural disasters  
50 in Indonesia necessarily delayed data collection requiring flexibility in both approach and  
51 management. Additional facilitators to collaborative working were the inclusion of senior  
52 academics and health professionals as co-applicants and lead researchers who could drive  
53 progress in Indonesia, the delivery of a research methods training course at study outset which  
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was delivered to both Indonesian researchers and PPI contributors and regular supervision by Skype and during study visits.

### Conclusion

Participants felt that there was potential value in the future use of PPI within Indonesian mental health services with careful consideration of individual contexts. Future aspirations of involvement enactment should ensure a central design and delivery role for third sector organisations.

**Data availability:** The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

## 5. REFERENCES

1. Trivedi P, Wykes T. From passive subjects to equal partners: qualitative review of user involvement in research. *Br J Psychiatry*. 2002;181:468-472.
2. Health Do. *Research – What's In It for Consumers? Report of the Standing Advisory Committee on Consumer Involvement in the NHS Research & Development Programme*. London1998.
3. Wallcraft J, M. B. *The Mental Health Service User Movement in England*. London2003.
4. Chamberlin J. User/consumer involvement in mental health service delivery. *Epidemiol Psychiatr Soc*. 2005;14(1):10-14.
5. Rose D. Service user produced knowledge. *J Ment Health*. 2008;17(5):447-451.
6. Grundy AC, Bee P, Meade O, et al. Bringing meaning to user involvement in mental health care planning: a qualitative exploration of service user perspectives. *J Psychiatr Ment Health Nurs*. 2016;23(1):12-21.
7. Brooks HL, Lovell K, Bee P, Sanders C, Rogers A. Is it time to abandon care planning in mental health services? A qualitative study exploring the views of professionals, service users and carers. *Health Expect*. 2017.
8. Rose D, Thornicroft G. Service user perspectives on the impact of a mental illness diagnosis. *Epidemiol Psychiatr Soc*. 2010;19(2):140-147.
9. Tambuyzer E, Pieters G, Van Audenhove C. Patient involvement in mental health care: one size does not fit all. *Health Expect*. 2014;17(1):138-150.
10. Bee P, Price O, Baker J, Lovell K. Systematic synthesis of barriers and facilitators to service user-led care planning. *Brit J Psychiat*. 2015;207(2):104-114.
11. Saraceno B, van Ommeren M, Batniji R, et al. Barriers to improvement of mental health services in low-income and middle-income countries. *Lancet*. 2007;370(9593):1164-1174.
12. Brinkerhoff DW. Accountability and health systems: toward conceptual clarity and policy relevance. *Health Policy Plan*. 2004;19(6):371-379.
13. Millar SL, Chambers M, Giles M. Service user involvement in mental health care: an evolutionary concept analysis. *Health Expect*. 2016;19(2):209-221.
14. Crawford MJ, Rutter D, Manley C, et al. Systematic review of involving patients in the planning and development of health care. *Brit Med J*. 2002;325(7375):1263-1265.
15. Whiston L, Barry JM, Darker CD. Participation of patients and family members in healthcare services at the service and national levels: A lesson learned in Dublin, Ireland. *Patient Educ Couns*. 2017;100(3):583-591.
16. Wallcraft J, Amering M, Freidin J, et al. Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers. *World Psychiatry*. 2011;10(3):229-236.

17. James K, Quirk A. The rationale for shared decision making in mental health care: a systematic review of academic discourse. *Ment Health Rev J*. 2017;22(3):152-165.
18. Disability UNDoEaSA. Convention on the Rights of Persons with Disabilities (CRPD). <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>. Accessed 19/9/2019.
19. Lempp H, Abayneh S, Gurung D, et al. Service user and caregiver involvement in mental health system strengthening in low- and middle-income countries: a cross-country qualitative study. *Epidemiol Psychiatr Sci*. 2018;27(1):29-39.
20. Brooks H, Lovell K, Bee P, Fraser C, Molloy C, Rogers A. Implementing an intervention designed to enhance service user involvement in mental health care planning: a qualitative process evaluation. *Soc Psychiatry Psychiatr Epidemiol*. 2018.
21. Cree L, Brooks HL, Berzins K, Fraser C, Lovell K, Bee P. Carers' experiences of involvement in care planning: a qualitative exploration of the facilitators and barriers to engagement with mental health services. *Bmc Psychiatry*. 2015;15.
22. Abayneh S, Lempp H, Alem A, et al. Service user involvement in mental health system strengthening in a rural African setting: qualitative study. *BMC Psychiatry*. 2017;17(1):187.
23. Gurung D, Upadhyaya N, Magar J, Giri NP, Hanlon C, Jordans MJD. Service user and care giver involvement in mental health system strengthening in Nepal: a qualitative study on barriers and facilitating factors. *Int J Ment Health Syst*. 2017;11:30.
24. Omar MA, Green AT, Bird PK, et al. Mental health policy process: a comparative study of Ghana, South Africa, Uganda and Zambia. *Int J Ment Health Syst*. 2010;4:24.
25. Rose D, Kalathil AK. Power, Privilege and Knowledge: the Untenable Promise of Co-production in Mental "Health". *Frontiers in Sociology*. 2019;4:57.
26. Brooks H, Sanders C, Lovell K, Fraser C, Rogers A. Re-inventing care planning in mental health: stakeholder accounts of the imagined implementation of a user/carer involved intervention. *Bmc Health Serv Res*. 2015;15.
27. Kleintjes S, Lund C, Swartz L. Barriers to the participation of people with psychosocial disability in mental health policy development in South Africa: a qualitative study of perspectives of policy makers, professionals, religious leaders and academics. *BMC Int Health Hum Rights*. 2013;13:17.
28. Saraceno B. Advancing the global mental health agenda. *Int J Public Health*. 2007;52(3):140-141.
29. Pacific MiA. Bali Declaration 2018: Transforming Communities for Inclusion-Asia Pacific. [https://madinasia.org/2018/09/bali-declaration-2018-transforming-communities-for-inclusion-asia-pacific/#\\_ftn1](https://madinasia.org/2018/09/bali-declaration-2018-transforming-communities-for-inclusion-asia-pacific/#_ftn1). Published 2018. Accessed 19/09/2019.
30. Idaiani S, Prihatini S, Indrawati L, Yunita I. Psychotic and pasung in Indonesian population: A national study. *Asia-Pac Psychiat*. 2015;7:17-17.
31. Minas H, Diatri H. Pasung: Physical restraint and confinement of the mentally ill in the community. *Int J Ment Health Syst*. 2008;2(1):8.
32. Irmansyah I, Prasetyo YA, Minas H. Human rights of persons with mental illness in Indonesia: more than legislation is needed. *Int J Ment Health Syst*. 2009;3(1):14.
33. Brooks H, James K, Irmansyah I, et al. Exploring the potential of civic engagement to strengthen mental health systems in Indonesia (IGNITE): a study protocol. *Int J Ment Health Syst*. 2018;12:49.
34. Quirk A, Lelliott P. What do we know about life on acute psychiatric wards in the UK? a review of the research evidence. *Soc Sci Med*. 2001;53(12):1565-1574.
35. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health C*. 2007;19(6):349-357.
36. James K, Brooks H, Susanti H, et al. Implementing civic engagement within mental health services in South East Asia: A systematic review and realist synthesis of current evidence. *Int J Ment Health Sy*. Under review.

- 1 37. Twinn S. An exploratory study examining the influence of translation on the validity and  
2 reliability of qualitative data in nursing research. *J Adv Nurs*. 1997;26(2):418-423.
- 3 38. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*.  
4 2006;3(2):77-101.
- 5 39. Charmaz K. Discovering Chronic Illness - Using Grounded Theory. *Soc Sci Med*. 1990;30(11):1161-  
6 1172.
- 7 40. Gray B, Robinson C, Seddon D, Roberts A. Patterns of exclusion of carers for people with mental  
8 health problems: the perspectives of professionals. *J Soc Work Pract*. 2010;24(4):475-492.
- 9 41. Tew J, Ramon S, Slade M, Bird V, Melton J, Le Boutillier C. Social Factors and Recovery from  
10 Mental Health Difficulties: A Review of the Evidence *The British Journal of Social Work*.  
11 2011;42(3):443-460.
- 12 42. Luitel NP, Jordans MJ, Adhikari A, et al. Mental health care in Nepal: current situation and  
13 challenges for development of a district mental health care plan. *Confl Health*. 2015;9:3.
- 14 43. Surjaningrum ER, Minas H, Jorm AF, Kakuma R. The feasibility of a role for community health  
15 workers in integrated mental health care for perinatal depression: a qualitative study from  
16 Surabaya, Indonesia. *Int J Ment Health Syst*. 2018;12:27.
- 17 44. Ramon S, Brooks H, Rae S, O'Sullivan MJ. Key issues in the process of implementing shared  
18 decision making (DM) in mental health practice. *Ment Health Rev J*. 2017;22(3):257-274.
- 19 45. Samudre S, Shidhaye R, Ahuja S, et al. Service user involvement for mental health system  
20 strengthening in India: a qualitative study. *Bmc Psychiatry*. 2016;16.
- 21 46. National Institute for Health Research: INVOLVE. NIHR Involve. [https://www.invo.org.uk/about-  
22 involve/](https://www.invo.org.uk/about-involve/)
- 23  
24  
25  
26 Published 2019. Accessed 7th November 2019.
- 27 47. Quinn N, Shulman A, Knifton L, Byrne P. The impact of a national mental health arts and film  
28 festival on stigma and recovery. *Acta Psychiatr Scand*. 2011;123(1):71-81.
- 29 48. Hanrahan C. Critical Social Theory and the Politics of Narrative in the Mental Health Professions:  
30 The Mental Health Film Festival as an Emerging Postmodern Praxis. *Brit J Soc Work*.  
31 2013;43(6):1150-1169.
- 32 49. Brooks H, Irmansyah I, Susanti H, et al. Evaluating the acceptability of a co-produced and co-  
33 delivered mental health public engagement festival: Mental Health Matters, Jakarta, Indonesia.  
34 *Res Involv Engagem*. 2019;5:25.
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## TABLES:

Table 1: Demographic information on study participants

| FOCUS GROUP (FG)         | SERVICE USERS |                          |     |                             | CARERS  |                          |        |             |
|--------------------------|---------------|--------------------------|-----|-----------------------------|---------|--------------------------|--------|-------------|
|                          | ID            | GENDER (M=Male F=Female) | AGE | DURATION OF ILLNESS (years) | INITIAL | GENDER (M=Male F=Female) | AGE    | CARING ROLE |
| FG 1 (NGO/SUPPORT GROUP) | SU 1          | M                        | 32  | 10                          | C1      | M                        | 67     | FATHER      |
|                          | SU 2          | M                        | 42  | 10                          | C2      | M                        | 45     | SIBLING     |
|                          | SU 3          | M                        | 36  | 15                          | C3      | F                        | 62     | MOTHER      |
|                          | SU 4          | M                        | 40  | 10                          | C4      | F                        | 61     | MOTHER      |
|                          | SU 5          | M                        | 30  | 5                           | C5      | F                        | 59     | SIBLING     |
|                          | SU 6          | M                        | 28  | 10                          | C6      | F                        | 47     | SIBLING     |
|                          | SU 7          | F                        | 46  | 23                          | C7      | M                        | 64     | FATHER      |
| FG 2 (URBAN SITE)        | SU 8          | M                        | 68  | 1                           | C8      | M                        | 24     | GRANDSON    |
|                          | SU 9          | M                        | 30  | 3                           | C9      | F                        | 43     | SIBLING     |
|                          | SU 10         | M                        | 27  | 2.5                         | C10     | F                        | 26     | SIBLING     |
|                          | SU 11         | F                        | 30  | 15                          | C11     | F                        | 32     | SIBLING     |
|                          | SU 12         | M                        | 30  | 4                           | C12     | F                        | 53     | MOTHER      |
|                          | SU 13         | F                        | 40  | 13                          | C13     | F                        | 41     | DAUGHTER    |
|                          | SU 14         | M                        | 40  | 1                           | C14     | F                        | 60     | MOTHER      |
|                          |               |                          |     | C15                         | F       | 45                       | MOTHER |             |
| FG 3 (RURAL SITE)        | SU 15         | M                        | 41  | 7                           | C16     | F                        | 46     | MOTHER      |
|                          | SU 16         | M                        | 34  | 10,5                        | C17     | F                        | 63     | SIBLING     |
|                          | SU 17         | M                        | 30  | 10                          | C18     | F                        | 42     | MOTHER      |
|                          | SU 18         | M                        | 22  | 5                           | C19     | F                        | 66     | MOTHER      |
|                          | SU 19         | M                        | 38  | 15                          | C20     | F                        | 70     | MOTHER      |
|                          | SU 20 IP      | F                        | 36  | 18                          | C21     | M                        | 69     | FATHER      |
|                          | SU 21         | M                        | 38  | 15                          |         |                          |        |             |
| SU 22                    | F             | 38                       | 1,5 |                             |         |                          |        |             |

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|  | <b>TOTAL N = 22</b> | <b>M =17<br/>F= 5</b> | <b>Average 38.8</b> | <b>Average 38 9.25</b> | <b>TOTAL N=21</b> | <b>M=5<br/>F=17</b> | <b>Average 51.7</b> |  |
|--|---------------------|-----------------------|---------------------|------------------------|-------------------|---------------------|---------------------|--|

For Peer Review

Figure 1: Example questions from the focus group schedule

- General opening question about experiences of mental health services
- Have you ever been involved in mental health services?
  - How?
  - When?
  - What were the benefits/negative consequences?
- Do you see any benefits of involving patients, carers and community in mental health services generally?
- Are there any negative aspects to involvement in mental health services?
- Would you like to be involved in mental health services?
  - What involvement would you like?
- What would help or hinder you being involved in your care/the care of family members?
- What are the facilitators/barriers to involving patients, carers and communities in mental health services?
  - Probe individual, organisational and cultural issues
- Is involvement relevant to your health?
- How could involvement in mental health services be improved in Indonesia?
  - What do patients/carers need to be involved?
  - What do health services need to do improve involvement?
- Thinking about your experiences of mental health services, what would have made the biggest difference to you?