



*Consulting with Groups  
of Consumers*

*Merinda Epstein*

*This is one section reproduced from the book "Doing it Together. A collection of approaches, experiences and purposes of an in Groups, Committees, Organisations, Networks and Movements". A resource of [www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au)*

# Consulting with Groups of Consumers

**Consultation (noun):** They've already made up their minds before they get through NSW. So by the time they get to WA they're just mining us for anecdotes. *MadQuarry Dictionary 2013 p. 8*

## *Introduction*

It has become currency for those who work in the 'system' - governments, bureaucracies, public inquiries and private instrumentalities - to seek to consult with groups of consumers. As an ever-growing number of consumers are drawn to the sector as workers, they too are charged with consulting with their constituencies. Indeed, there is generally an insistence that consultation is central to the work if they are to properly 'represent'<sup>28</sup> those they serve. Despite the limitations of consultations, there are ways of consulting with groups that are better than others and experienced organisations in the consumer sector have historical wisdom that is special and substantial.<sup>29</sup>

## *'Stakeholders'*

Consumers should never be seen as sausage-holders in the consultation process; the language of 'stakeholders' employed by those conducting consultations with groups of consumers is deceptive. Wadsworth describes consumers as the *Critical Reference Group* (CRG) (1997). Although this is a mouthful it is important; we all know processes where the voice of a whole group of consumers translates into one set of notes whilst discussions with five 'influential others' generate five additional sets of notes and then are reported about as if they have equal value and numerical strength; this is not equal treatment nor is it democratic. So the 'size' of the stake is important.... Further,

consumers are often not 'stakeholders' in their own lives; there are multiple dependencies to take into account which deny our power as 'stakeholders'.

## *Consultation: The Process*

Having established that consulting with groups of consumers is fraught, it is perhaps also necessary for consumers to be informed about the ways consultants, be they 'others' or employed consumers, go about this process.

### *1. Negotiating the Consultation*

**External Consultants:** companies and sometimes community organisations win tenders to conduct consultations with groups of consumers mostly brought together for the purpose; sometimes they are required to consult with established consumer groups. Whichever, the ethics in regard to practice and to negotiated contracts needs attention; sometimes contracts are drawn-up with consumer organisations that can do the consulting 'in house', having infrastructure, resources and experience to conduct consultations in a timely and cost-effective way.

The contract is frequently made with the lowest commercial bidder; a company/organisation able to make such a bid can - either - be sagacious and efficient - or - because they don't understand the consumer imperative - or - because they're cutting costs to win the bid and skimp on the provision of safe, useful, timely, properly funded collection of consumer experiences and expertise. Consulting

is *always* political; choices are made by both contractor and consultants about who matters most and who must be seen to matter most; hence, tokenism is always a possibility.

From the long list of attributes and experiences required in the tender, the imperative to consult respectfully with consumer groups (and groups of consumers) frequently falls back into a pack of other interests. Knowing how to listen to distressed and powerless, angry and disillusioned, silenced and sometimes shrill people is not prioritised; other specialist skills are not demanded. It is wrongly assumed that these competencies can be learned 'on the job' by non-specialised consultation firms; organisations, governments and instrumentalities that want a good job completed have a responsibility to ensure that competent inquiry is mandated in the bidding documentation.

**Organisations/governments employing consultants:** Especially during times of economic contraction, there is a responsibility for organisations to determine that sufficient money is available to consult with consumers and consumer groups, in a democratic way and respecting that they are the critically important group. Such consultations need to be uniquely centred, to ensure consumers are heard when they are competing with 'experts' perceived to have authority.

External consultants may require education, sanction when necessary, clauses in the contract, employed consumers to guide them and help them understand the sector, including warnings about valuing different expertise selectively and shining a light on consumer accomplishments, the importance of the critical consumer perspective (Grey 2014) and the consumer body of knowledge (Roper).

Tendering organisations need to monitor a tendency, amongst outside consultants, to make (often deprecating) judgements about the 'quality' of knowledge of groups of consumers, based on spurious (community and sometimes sector) assumptions behind notions like '*serious mental illness*', '*real patients*', '*grassroots*', '*the most vulnerable*', diagnostic categories, elitism, '*levels of functioning*', '*professional consumers*', or even chronicity and recovery. Such notions are often mischievously introduced by people having their own agenda - 'others' and sometimes consumers. External consultants often have very little knowledge, or even the independent capacity to be critical about what is presented to them as '*common sense*'.

Expert consultation firms are sometimes attracted to tenders because of personal experiences of mental illness in the family life of senior staff; mental illness as perceived by family and friends *is not the same* as mental illness understood/experienced by (groups of) consumers. This disconnect can, sometimes, lead to a witches brew of half facts and half-truths, as carers and family members hear consumer groups selectively and filter everything through a 'carer' lens. Although family members and 'carers' have a valid point of view, *they are not the Critical Reference Group* and they have a great deal more power and status than many consumers. Many external consultants, unfamiliar with the sector, will fuse the family/carer/ consumer perspectives. History has taught us that this, on its own, can derail a consultation process. It is essential that tender processes be overt and gauge the perspectives of the central consultants who will work on the project beyond their formal qualifications and experience.

**Consumers:** Increasingly, consumers are being asked to consult with 'their group', 'consumer groups', 'consumers in groups', service user groups and Consumer Advisory Groups. The way the process is articulated and then carried out is important; for example, we can 'hear' things in undemocratic ways when processes are run without sufficient funding. This doesn't mean that you can't find out what *'people truly think'* more cheaply; with goodwill and knowledge, a lot is possible! It does mean that when groups negotiate with the organisations undertaking the consultation, they should make sure that the money is going to the right places so that consultants can make ethical decisions about methods and priorities. We also have a responsibility to educate the services and agencies we work for about good practice<sup>30</sup> and consumers about what is acceptable in terms of giving time and effort to help organisations, governments, instrumentalities find out what they want to learn.

Because of life and service history, many people diagnosed or labelled with 'mental illness' don't fully appreciate they can say 'no'; they don't always realise they don't have to talk in the first person, that they can demand - either - confidentiality - or - to be named if they want to make a proud statement to the world; *either is their prerogative*. Sometimes groups prefer a group identity rather than individual ownership of particular group wisdom, which fundamentally is a democratic stance. Along with proper, respectful funding, such macro-issues need to be negotiated with consumer consultants' organisations *before* the consultation; playing catch-up on substantial matters rarely works.

## 2. *The Process: The Variables*

It's impossible to offer a recipe for consulting with groups of consumers; a first variable is whether groups are established and affiliated with an organisation or whether consultants pull in a group of people without any real *'groupness'* other than being in the same place at the same time and having a shared investment in mental health provision.

**The group created for consultation**<sup>31</sup> may be a group of people with *experiences* of being diagnosed or labelled with 'mental illness'; and/or a group of people who *identify* as being diagnosed or labelled with such; and/or people who identify as *carers* of people diagnosed or labelled with 'mental illness'; and/or a group of people who identify as *healers* of those who are labelled with or diagnosed with such; and/or... Although becoming a 'group' for the purpose of the consultation, we may be more or less 'pure' in the sense of our distillation of experiences of 'mental illness;' the group experience of consumers on their own is very different to that of consumers being together in a group with family members, clinicians and administrators.

The above groupings have different amounts of institutional power, arguably those of consumers the least. As well, in such artificially created 'groupness', different axes of social and institutional power cross: social class, illness, race, sexual preference, education, disability, gender, ethnicity, diagnosis, poverty, professional status, position, experience of the world, command of English and capacity to tell a heart-wrenching story. Such sets of political relationships offer complex combinations and are daubed in power differentials generated by personal connection.

As intimated before, the most powerful probably won't be part of a group anyway; they will most likely get the consultants' ears quite separately, maybe over dinner, the previous or following evening, possibly including (some) consumer(s).

**Groups connected through organisational affiliation;** this might mean local groups connected as satellites of a consumer organisation, for example VMIAC; or groups that are part of a community or a community mental health organisation. The consultation process is either run by consumers (if it's a group supported by a consumer organisation) or sometimes by 'others' (if it's a group supported or affiliated with a health or community organisation that does not have a consumer workforce.) Organisations supporting a consumer workforce might have the inquiry run by consumers. Sometimes governments and their agencies engage the community sector or consumer organisations to consult with 'their' groups on their behalf.

### *3. The Process: Time, money – macro considerations*

Beyond careful negotiation with the funders of the consultation, it is important to ask specific questions about what is most important for the people for whom the service/group/organisation/committee exists:

**How much time and money have we got?  
What can we realistically do with the time and money that we have? (examples only)**

- Do we most want to speak to consumer groups or bring groups of consumers together? What are the pros and cons?
- Is it most important to spend this money travelling to as many consumers as we can?

*And/or*

- Can we sub-contract out the collection of data to consumer groups to collect information for us? Payment? Catering? Travel? Report writing? Any down sides? *And/or*
- Is it most important to employ consumers to provide a critical consumer analysis of the findings or to work out whether our filtering, of what we thought we heard, was the best we could possibly do? *And/or*
- Is it most important to ask really deep, telling, and provocative questions of a small group of consumers who have really thought about the issues we are exploring? *And/or*
- Is it most important to tape and transcribe, so we hear the small voices and the detail that might surprise us and that we might miss otherwise? *And/or*
- Is it most important spending money to advertise in electronic ways to get to groups of young people? Or a wider slice of the consumer population? Or specific populations of people with 'mental illness' or...

**How much of our decision-making is/must be political?**

- Does the funding body need us to demonstrate to 'stakeholders' that we have been 'thorough' – i.e. 'been seen' all over the place' and having spoken to as many groups as possible? Is this sound practice from a critical consumer perspective?
- Are there groups who will 'scream' about not having been 'consulted'?
- Are there individuals who have the power to cause problems if their wishes/ideas are not overt in the report? Do they have pet groups?

- Are certain groups more available? For example affiliated to a peak body or easily accessed by an organisation? What's the ethics of this?
- Are some groups seen as more 'core' to the public mental health agenda or core to some other political agenda - pharmaceutical companies, for example? Ethics again?

#### **What is the relative visibility of some groups or persons invited to a consultation?**

- What about people who are locked out of public services?
- What about people who are told they are 'bad' and not 'mad'?
- What about people who have a lot to say but totally refuse any sort of psychiatric intervention?
- What about people who use GPs or private services?
- What about people who support each other, using relationships in the community?
- What about people who simply wouldn't relate their struggles to anything personal at all - they see them as social and political?

- What about minority groups; e.g. LGBTI or CALD or Aboriginal, young or old (examples only)?
- What about groups that fit into categories we don't like very much; e.g. support groups around different diagnoses; groups supported by medicalised agencies or sponsored by drug companies; twelve-step groups or groups that oppose all forms of psychiatry?
- Does 'chasing-down' minority and hard-to-reach groups also have a negative edge? How much value do consumer organisations get from the effort outlaid and is there a risk of devaluing minorities' and hard-to-reach groups' refusal to be involved in processes that they consider a waste their time? Whose agenda is it?

#### *4. Collective Wisdom*

Over the thirty-plus years that the consumer movement in mental health has been active, we have learnt a great deal about consultations - sometimes by getting it wrong, or by not understanding the political agenda or, simply, by not buying in the skills that were needed. It has become obvious that there are (at least) four ingredients to involving groups of consumers in human inquiry:

*“People [diagnosed with ‘mental illness’ are ‘the experts’ about their own life and being. [They] carry the wisdom to best articulate their own needs if they are accorded the time, space and means to do so.”<sup>33</sup>*

- Understanding the importance of the Critical Reference Group;
- A critical consumer perspective;
- Skills in inquiry, questioning with open questions which allow deeper exploration;
- Time and money to allow people to best answer questions for themselves and in their groups without feeling hassled or 'used'.

### *5. Some useful information gleaned from experience*

**Insights about method:** People who have not been listened to and who have had a history of horrible things written about them need notes that are taken to be transparent, preferably written in front of them; they need an opportunity to see they have been recorded accurately and a good process to correct wrong interpretations.

- Consumer organisations/groups know through group experiences how to consult. This expertise is rarely appreciated or actively sought. From things as simple as understanding smoking culture, to appreciating the importance of consumer subculture, groups tend to be an underutilised resource.
- Consumers often need tables in front of them, both to take notes and to 'hide behind'. This is important for many people who have had their realities challenged and have experienced demeaning 'therapy' and programs requiring chairs in horseshoes and mortifying embarrassment.
- Bringing groups of people together creates challenges. People recover in their own way. People have different experiences, politics,

families, tolerance levels and education, experiences of shame and grief and priorities determined by their own struggles. Sometimes we can finish each other's sentences and at other times we disagree and shame each other. These disparate needs must be understood and valued as part of 'real lives' and real group dynamics.

- People who haven't been listened to by services may clamour to be heard in consultations; people may tell and retell their stories until they feel heard<sup>34</sup>. This creates opportunities for consultants to demonstrate their listening skills and lateral thinking. Respectful approaches to different listening need to be built in and handled well, especially considering other consumers may get frustrated.
- People have been indoctrinated in the ways of 'clamour-hearing' in mental health services - dramatizing stories to outdo each other is not pathology and is not dishonest. It is a pattern that works in services which are blind to subtlety. Seeding it in consultation is a skill.
- Ideally, consumers should be able to see that their words have been interpreted accurately but sometimes taping and transcribing is not possible, so consultants need to demonstrate their integrity in another way, the operative word being '*demonstrate*.' Talking at consumers about the integrity and past performance of a consultancy firm, for example, doesn't cut it.
- Nobody is a truly objective scribe; e.g. someone volunteering to collect a group's discussion on butcher's paper might be well intentioned, benign or manipulative. Consultants need to think about this.

Allocating a 'silent scribe from outside' is maybe the best we can do, with a least disruptive process for people to say "No, that's not what I said".

- Not everything that is useful is an anecdote of 'mental illness' or 'psychosis' or services or... Some people speak through narrative but others don't. It's important to hear both. This also means that analytical consumers might, but don't necessarily, know more than those who prefer narrative. It's a style difference and not necessarily a difference in content or import.
- Trawling for anecdotes is lazy consultation; experienced consumers know which ones work and have a cache that gets used and reused.
- Transparency in consultation recording is vital. For people who have been watched to within a cell of their bodies, have had terrible judgemental words written about them and don't trust processes of recording their opinions honestly in consultational integrity. Consultants tapping away on their notebook computer and creating notes for their eyes alone is not good process. Consultations need to be safe and this isn't safe for many.
- Taken to an extreme, the process of correcting mistakes in interpretation strengthens the loudest and further silences the quietest. This dynamic must also be taken into account and the skills of those who are creating a listening and respectful environment become more important.
- If you come to a group of consumers ostensibly to listen and end up *talking at* people instead, you'll get short shrift from the old campaigners and no response when you eventually inquire from others. A consultation implies listening and not talking more than necessary.
- There is one exception to this; the method of inquiry employed in the *Understanding and Involvement (U&I) project* emerged as researchers found that people needed relationships and conversations to enable their opinions to form and find oxygen. Before that they were intimidated into not believing they had anything to say. As the consumer researcher had a relationship with other 'patients', people did start to speak and speaking nearly always turned into a gush of things that were previously being self-censored and dismissed as unworthy. Conversations between consumer consultants and people in acute units, for example, don't constitute 'bias,' rather, they enable. In the U&I project, conversations were recorded and returned to consumers to be approved before being written up in the book as a conversation, with the researcher's and the 'patient's' voice both prominent.<sup>35</sup>
- People get frustrated by different things; don't ever just listen to the frustrations of those with most power to articulate their needs.
- Executive summaries almost never summarise the contents of consultations with groups of people. They simply repeat the special interests of someone, usually not a consumer, who has already had too much to say.

Consumers working 'in the system' only get to be or talk with or learn from those who have not been 'gate-kept' out of the system, got away with refusing psychiatry completely, or who use private services or primarily GPs. These groups are too often absent from review and their views are lost to the system.

- Outside the public system, consumers have almost no voice. Organised groups are often captured by medicalisation, drug companies, health insurance companies etc. The voice needs to be heard; how to do it with integrity is the question.
- Don't ever go to consult with a group without a way to record people's responses. If you want to go to sell a message, don't say it's a consultation. Consumers develop very astute detectors of bureaucratic nonsense.
- If people (including consumers) really want to know something, it is often better to drill down with a small group of consumers who have thought about it than waste the time of a large group of consumers who haven't thought about it and perhaps don't want to.
- People '*not-knowing*' is worth recording. People change their minds in the group process and this is also interesting. Sometimes, we come to understandings only as we start to say the thing we thought we believed and it was found wanting in articulation.

### *Groups of consumers, carers and clinicians: Joint Consultations*

- Combined groups of consumers, service providers and carers must have a different purpose. It's important consultants know what

they want and from whom. Bringing groups together as a cost saving effort will not work.

- Neither carers nor clinicians are the *Critical Reference Group*; maximum effort must be made to enable the voice of consumers in mixed groups.
- Sometimes carers and clinicians make a song and dance of 'listening' to consumers first; this is just a different way of wielding power. It doesn't matter how many times you speak if the 'listening bit' is an 'act.'
- Sometimes clinicians feel silenced in such groups; they don't know where they stand and in particular, our allies don't want to take over or speak for us. It's important for consultants to give permission for our allies to say what they need to say.
- On the other hand, some clinicians will just demand an audience elsewhere and they will, sure enough, be heard; the ethical question for consumer groups and organisations is: should we follow suit and demand a separate audience and what are the consequences thereof?
- The term '*lived experience*' merges the voice of consumers and carers, which may be a real problem for consultations.
- Power relationships in groups are of paramount importance for consultants and they must actively engage in these; joint consultation groups should, at least, have comparable numbers of Consumers, Carers and providers/clinicians/workers/managers.
- Many carers are consumers and many consumers are carers; what is important is the perspective from which they choose to speak

and that they do so from the *right premise*. 'Carers'/family members say (often privately), "we have only a little bit of mental illness. My daughter has Schizophrenia and it's disrespectful for me talk about my depression in this context". What is the agenda behind this and what does it mean for mixed group consultations and what are the ethics of projecting one lot of suffering on to another? Group dynamics must deal with this with integrity; hearing from the 'most vulnerable' by giving the carers of 'the most vulnerable' a lot of air space is suspect.

- Many clinicians are consumers; they must speak as clinicians if they are clinicians *for the purpose of the consultation*. Clinicians who are not 'out' as consumers can not have a critical consumer perspective (Grey).
- We all need permission from our relatives if we want to use their stories; consultants can and must monitor this. This goes both ways and is actually very hard; without permission, both consumers and 'carers' need to tell their story in a 'bubble' and sometimes we simply can't tell our story without implicating others.
- Some carers are so desperate to be heard that their stories are drama. It is really important that consultations don't turn into carers telling more and more desperate stories. This is not about their right to be heard but rather that it silences smaller but important stories from consumers and other carers. Probably this applies to some consumers as well. Is it about group processes that demand the dramatic in order to be heard?

### *Consultants' Perceptions challenged*

- There is no such thing as a 'real' consumer; no-one's experiences are more real than anyone else's.
- Whatever 'mental illness' is, people make decisions about the degree to which they identify with this aspect of their lives; whether for specifically political reasons, community acceptance, self-esteem or any other reason, it's a person's own decision how they choose to spend time and with whom. Groups that work are self-selected.
- Being 'out' as mad, crazy or loopy is also an individual choice; no therapist, clinician, community member, person conducting a consultation has a right to pathologise people's right of association.
- There's no such thing as *Serious Mental Illness* defined by diagnosis; diagnoses are used for public service gatekeeping and many people don't find talking about diagnoses at all useful; many clinicians don't find diagnoses useful either, but those in the public sector are forced to use them.
- Many consumers prefer to use the term 'experiences' rather than the medical term 'symptoms'.
- We are all (potentially and pragmatically) both grass roots consumers and consumer leaders; these are never two different groups.

- People who use private services are not by definition stupid or co-opted or '*not real consumers*' or lacking the grunt to get out of a trap they are not locked into. Generalised commentary on psychiatry by groups lacking input from the private sector and GPs is deficient.
- People who hate psychiatry or don't find it useful, who criticise radically, who call forced treatment 'torture', who critique power arrangements in psychiatry, who distrust medical imperialism and who find answers in the community or alternatives are not radical extremists. Generalised commentary on psychiatry by groups lacking input from the anti-psychiatry lobby is deficient.
- Many consumers are understandably annoyed by tokenism; when consultation

after consultation with groups of consumers changes nothing, people become apathetic. Who can blame them?

- The most fundamental group for many people is 'the family'; people labelled with 'mental illness' who are obvious in the community are often not the only member of the family to be diagnosed with a 'mental illness' or have a 'mental illness' that is not diagnosed. It is a myth to believe that families are always normal and that the person with the mental illness is the unexplainable anomaly.

### Research/Evaluation<sup>36</sup>

People often call all groups that are formed to collect information '*focus groups*', a misuse of this term. In this chart Yoland Wadsworth identified the difference:

<i>Group Interviews</i>	<i>Focus Groups</i>
... as old as groups and inquiry	... originated in the late 1950's out of market research
... may range from unstructured to more highly structured (a series of questions)	... orient around a single issue or topic
... may be naturally occurring groups; on site groups; recurrent/longitudinal groups; representative groups	...group of strangers who meet once only at researcher's venue
... size can range from 3 to ??? (public meetings may be 100s or so)	... size 4-12 (6 - 8 favoured)
... range in formats (e.g. Delphi, nominal, planning, therapeutic, advisory, action, brainstorming, consultative, indigenous etc.) depending on purpose	... single format and purpose (to explore range of views or experiences around a single matter/topic)
... participants may be homogenous or heterogeneous	... participants are homogeneous on the single topic
... participants may discuss, plan, agree, rate/disagree, rank items, problem-solve, as well as collect views	... participants only give their views
May operate as a quasi-survey	... can never operate as a survey
Researchers as questioners	... researcher as moderator

## *Both Groups...*

- Data derives both from individual views and from the effects of group interaction;
- Best to go for concrete experiences and perspectives, rather than abstract attitudes and opinions;
- Data are the transcripts of the discussions;
- Data is voluminous!
- Analysis needs creative thinking.

# Endnotes

28. Consumers now have a strong critique of the concept of 'representation' in many contexts (see Our Consumer Place book on Mad Meetings). Although the critique is primarily concerned with 'others' (Grey 2012), demands for consumers to 'represent' also applies to employed consumers' acquiescence to demands to represent others and justify it by poorly thought-through or tokenistic consultations. Representation of groups of people, or even a class of people, is usually not possible given the resources available to consumers regardless of whether we are employed in the system or not. The nature of 'lived experience' is that we carry our understandings, hurts, freedoms, politics, grief, shame and childhoods with us regardless of how many other consumers we may or may not have spoken with. We sieve all new information through our own particular experiences and that is not necessarily ameliorated by consultations no matter how good the process. Denying this will make it worse.

29. A snapshot of this is the Victorian Mental Illness Awareness Council (VMIAC) and the capacity to attract group members to be bothered sharing their opinions by sausage sizzle technology. That is: (1) The questions have to be worth answering; (2) The venue needs to be conducive to sharing a consumer perspective; (3) Ideally consumers need to be the question askers; (4) There needs to be provision for smoking; and (5) food is not a bribe, it is respectful.

30. See Our Consumer Place publication Mad Meetings <http://www.ourcommunity.com.au/files/OCP/MadMeetings.pdf>

31. See table at end of this 'chapter' by Yoland Wadsworth

32. Questions that can't be answered by a simple yes or no

33. Developing Effective Consumer Participation in Mental Health Services: The Lemon Tree Project (1997) VMIAC.

34. Wadsworth Y. (ed.) The Essential U&I, Victorian Health Promotion Foundation, Melbourne 2001.

35. Wadsworth, Y. (ed.) 2001, The Essential U&I Victorian Health Promotion Foundation

36. Yoland Wadsworth

- Do It Yourself Social Research, Wadsworth Y. 2010 Allen & Unwin Sydney, Australia
- Every day Evaluation on the Run, Wadsworth Y. 2010 Allen & Unwin, Sydney, Australia
- Building in Research and Evaluation: Human Inquiry and Living Systems, Wadsworth Y., 2010, Action Research Press and Allen & Unwin, Melbourne, Australia

