

❖ Chapter 5: Evaluation Findings

This chapter presents the findings of the baseline and evaluation interviews conducted with staff and consumer participants in each of the five sites conducting demonstration consumer participation projects. Baseline interviews aimed to collect information about understandings of consumer participation and expectations of the demonstration project prior to the implementation of the demonstration projects. Evaluation interviews were conducted three to six months after the implementation of the demonstration projects and aimed to explore staff and consumers' experiences of the project, and to map changes in understandings or attitudes toward consumer participation. We will present the findings of the baseline interviews, then evaluation interviews, and then summarise key themes across both sets of findings. The table below provides a summary of the participants in baseline and evaluation interviews.

	Baseline		Evaluation	
	Males	Females	Males	Females
Key staff	6	3	5	2
Key consumer	3	5	2	4
General staff	11	13	10	7
General consumer	8	9	10	8

5.1 Baseline Findings

All sites were visited prior to commencement of their projects and interviews were conducted with staff and consumers. The baseline interviews were aimed at identifying current levels of consumer participation, understandings of consumer participation, interest in consumer participation, awareness of the project, expectations of the projects, training and capacity building needs, and perceived barriers to consumer participation. In addition, the baseline interviews were included to provide data to measure any changes as a result of the demonstration projects.

5.1.1 Awareness, Understanding and Interest in Consumer Participation

The term 'consumer participation' did not resonate with many service users — few had heard of the term. Service staff were more likely to have heard the term 'consumer participation', but only a few had any prior experience with consumer involvement in the drug treatment field.

While few treatment service users had heard of the term 'consumer participation', the majority of service users interviewed said it would be a positive shift if consumers had a voice within the treatment services they access, as the following examples suggest:

'It sounds like a good thing...yeah for sure. Because we're the ones that are using it so that makes sense.' (Male consumer)

'You need a service that is run by workers and what-not, but I really think the service would benefit more from people who are currently in that position ... consumer reps can be a sort of focal point between the guy that runs the service, like between the workers and the people who use the service. I also feel like we're a good resource to help the community understand services.' (Female consumer)

In one instance, and in response to an invitation from the service, the local drug user organisation had organised and delivered training workshops for both service staff and consumers around the theme of consumer participation. Here the notion of 'consumer representative' (as 'advocate') began taking hold:

'To give those a voice that don't feel they have one, and a place to voice it on that is like them... like they come to me instead of coming to a staff member, they can come to someone who's been there and done that, even if the staff member has been there and done that it's still a bit intimidating to people... it's to advocate for them.' (Consumer)

Indeed, as will be reiterated throughout the report, those services that involved their local drug user organisation as a means of improving knowledge, implementation and support vis-a-vis 'consumer participation', demonstrated consistently higher levels of understanding among their consumers than those services that did not. In the instance cited above, a key staff member later described the drug user organisation's involvement — including their assistance recruiting the consumer representative — as a highlight of the demonstration project, commending their 'highly professional' approach. As the following comment suggests, even the distribution of printed resources assisted consumers' awareness, not only of consumer participation but of their relevant user organisation:

'And I got a folder [of information from the drug user organisation] ... I've sort of gone back through the folder and had a bit of a look at it, and I sort of relate to what they're trying to do for people... So it was really good to sort of finally realise that there is an organisation that's trying to help people in getting their needs met.' (Consumer)

The majority of staff also supported the concept of consumer participation and believed it offered a range of potential benefits, for example:

'...So like it's one thing to give a service, but if it's actually not a service that is useful to consumers then it's futile. So therefore I see them [consumer representatives] as actually directing us to make sure that we are providing proper services...' (Staff member)

Some staff felt services would gain new and alternative ideas about the service from their consumers:

'You just get, you just get different views... the client views as opposed to what, you know, we can try and think that we would know how they are thinking or how they felt. See they can, they might come up with completely different ideas of how to better the service... To get just like stuff that we might not think of that they would think was good, or stuff that we do that actually irritates

them, they could bring it [to] our attention. I mean obviously we can't change everything but just new eyes.' (Staff member)

The majority of sites, while committed to consumer participation, did not currently have consumer participation at the organisational level. Further, most services and their staff had little engagement with the service users outside of clinical interactions. One community drug treatment service did have a drop-in centre where staff and other consumers could meet and talk. This service also offered programs for their consumers that were not explicitly treatment orientated, but included sport and art activities.

The residential rehabilitation service did offer many opportunities for staff and consumers to interact on a daily basis. The staff and managers of the residential rehabilitation service described their service as having a range of consumer activities. Indeed, unlike the other services, they considered that all aspects of their service were informed by a consumer perspective.

Treatment service consumers and staff were asked what skills and characteristics consumer representatives were likely to require. These included good communication skills and experience with drugs and treatment, and having a capacity to communicate with staff and consumers was regarded as central, as the following example illustrates:

'A good candidate... someone who is a good communicator. I don't mean written skills, I mean someone who can talk to people. Someone who... I guess it is a lot of the things we look for in our staff. Rather than employment qualifications, we're looking for people who get along with our client group - not everyone can - and can communicate effectively with us. And someone that's been around long enough to know what the issues are and have a bit of perspective on them.' (Staff member)

Other qualities highlighted included being non-judgmental, having determination, courage and confidence:

'Well, good people skills, communication skills and to be confident within themselves as well as having the inside knowledge of what's going on. And I think confidence is a big thing and the ability to articulate exactly what you mean.' (Female consumer)

The notion of confidence seemed particularly crucial, with consumers often interpreting their peers' 'bad', defensive or antagonistic behaviour within treatment settings as symptomatic of a lack of confidence. This interpretation of others' behaviour was not pejorative but rather proffered as further evidence of the [perceived] advantages of consumer participation — in this instance via a consumer representative:

'I think because the main thing I've noticed with people on methadone is the, you know, the 'scuse my language, but they're always like "oh these people are cunts, they don't listen, they're fuckin' dogs, you know, they don't let me get my dose, (even though I haven't been there for three days)". But you know, and I just think by giving them the confidence to come to somebody and talk, it may help them to have the confidence to improve their life as well.' (Consumer)

A significant number of consumers believed that other consumers were able to provide real-life experiences of drug use and treatment and were therefore likely to offer treatment services opportunities to enrich their programs and services in ways that would be beneficial to their consumers. It was common for consumers to compare knowledge derived from lived experience with drugs and drug treatment positively in comparison to knowledge developed through formal education and training:

'...some people that aren't in the scene wouldn't have a clue... Like you have new people coming straight out of school that have never bloody used the drugs. And like how are they going to be able to tell you anything... Whereas us on the other hand, we're in here and we know...' (Female consumer)

"...You wouldn't really want someone representing you that had to train to represent you because it comes back to the experience thing and they'd be learning out of a text book." (Male consumer)

The TSU Project: Phase Two aimed to develop organisational consumer participation; however it was not uncommon for staff and consumers to frame their project aspirations in terms of support and self-help and not in terms of organisational decision-making.

Knowledge of the TSU Project: Phase Two was minimal among staff and consumers. In most cases consumers had no prior knowledge of the demonstration projects before the interview and in no cases were consumers consulted or included in the development or writing of the project proposal.

This was also the experience of staff who were often only hearing about the project just prior to the interview or at the interview. In many cases, a manager or one or two staff interested in consumer participation had written the project proposal in isolation and not discussed it with other staff:

"... If you are not involved in the planning it can have the effect of resentment, because the people that often end up doing the groundwork are workers like myself. They're not the high level where you can have the ideas and the vision and all that. But the people who tend to have to run with it and implement it are the people that may, and do in some instances, have the least say." (Female staff member)

The model of consumer participation used in the TSU Project: Phase Two notes the importance of involving staff and consumers from the outset. While this may be ideal, very few of the sites had degrees of engagement with their consumers to make this practicable. The nascent state of consumer participation in the drug field will likely require staff or managers with a particular interest to play a central role in initiating consumer participation.

While failure to engage consumers from the outset may be able to be explained by low levels of existing engagement, it is less clear why some services did not seek to inform and engage their staff in the early stages of developing the projects. However the failure to include staff and consumers from early in a project may have ongoing negative impacts — as staff and consumers feel disengaged and imposed upon.

One site had actively involved staff from the outset and, although not all staff were interested, a number of staff chose to become actively involved in the project, working together to develop the proposal. While they did not expect to achieve a great deal in six months, they were committed to continuing to build consumer participation with a long-term aim of changing the service culture.

5.1.2 Stability

Among both staff and service users interviewed at baseline, the subject of 'stability' was interpreted exclusively as a question of consumers' suitability for roles as representatives or advocates. Both service users and staff proposed that consumers who took on roles as consumer representatives or advocates would need to be 'stable'. While the definition of 'stability' invariably reflected the service's treatment

ethos —typically ‘abstinence’ or ‘harm reduction’ — it was nonetheless used and understood as an attribution belonging to individuals.

What constituted an individual’s ‘stability’ thus varied between individuals and drug treatment services. Staff who worked in services that promoted harm reduction were, for example, more likely to frame stability in terms of reduced use or being on pharmacotherapy. Services or staff who were committed to abstinence as the goal of drug treatment tended to define ‘stable’ as relating to no longer using drugs or pharmacotherapy. During baseline interviews the range of views regarding stability was similar among both staff and consumers, including among those individuals identifying as current ‘users’. As one consumer remarked:

‘Well it depends on your lifestyle as to your commitment level.’ (Consumer)

5.1.3 Ex-drug Users

Staff and consumers were also asked what, if any, role they felt ex-users had to play in consumer participation. Many of the consumers felt that ex-users would bring valuable experience to the role and were therefore broadly supportive of their involvement. However, some consumers felt that ex-users eventually preferred to cut ties with the drug-using community and therefore could end up disconnected from current users and not really representative of their needs.

A number of staff at one service were negative about the inclusion of ex-users on the grounds that they often had strong preferences for abstinence-based and 12-step approaches to drug treatment and were opposed to harm reduction approaches. They were concerned that if ex-users were involved in consumer participation a diversity of views and needs would not be considered, in particular the voices of and the issues for consumers who continued to use drugs.

5.1.4 Capacity Building and Training

While some staff believed consumer representatives would need some training, others did not identify specific training or support needs. Staff tended to focus on support in dealing with other consumers, and very few staff identified the need for the management and staff to undergo training. The following example is fairly indicative of attitudes among staff:

What skills do you think will be needed to be developed among both staff and consumers?

‘Oh I don’t know, I think the skills are just... I think the skills are there, people [staff] just have to work their head around... yeah I think... I’m not... I don’t know about the consumers, although I think the skills are probably largely there anyway. A lot of people have done a lot of stuff with treatment programs and support groups and stuff.’ (Male staff member)

For some staff answering the same question, the issue of additional training was less important than attitudinal change:

‘I think it’s attitude. Yeah, I think because they... what the staff have been doing here, I think it’s sufficient for... like for how they do things.’ (Female staff member)

‘Maybe a bit more open just to try, see how it goes.’ (Male staff member)

5.1.5 The Role of Consumers in Organisational Decision-Making

Staff were asked whether they would be comfortable having consumer representatives on interview panels and staff development reviews. Initially, many staff expressed concern, particularly in relation to performance reviews, which is consistent with the findings from the TSU Project: Phase One. In this phase, however, few staff were completely opposed to the idea and a small number saw it as having a range of positive benefits:

What would you think about having a client or consumer involved in staff recruitment?

“I would be quite favourable. But it would depend on, I mean I just know from my experience there are some clients that wouldn’t be in a position to make an informed decision. But there would be a couple that if they had some experience in the organisation, did some mentoring, they would certainly be valuable in that role.” (Staff member)

When recruited to his current position, one senior staff member recalled positively the presence of a consumer on his interview panel some nine years ago, noting the strong message this had conveyed to him that he would be there to work not just for management but for the service users.

Nonetheless, such support for higher level consumer participation was not uniform, particularly around the issue of staff appraisals. One worker at another service was asked how she would feel about having consumers involved in staff performance reviews:

‘Would I like them to review me? If it was current residents, it would definitely make me uncomfortable.’ (Female staff member)

5.1.6 Expectations of the Projects

Staff and managers were consistently circumspect in their expectations regarding the possible short-term benefits of the demonstration program. Opinions varied more widely, however, with regards to its longer-term possibilities. The following examples illustrate the optimism and sense of possibility felt by some staff regarding the latter:

‘... right across the board I think the benefit is that people [consumers] might well see that the service is theirs and that they have an ability to speak about what they need. And, of course, then the service gets feedback about things that you don’t necessarily see yourself and the process of that, if it works successfully, is empowering.’ (Male staff member)

‘I would sort of hope is that, at the very least, what we would get is a better rapport or connection to the, you know, the consumer group, which gives us better insight into programming and the consumer group gets better programs.’ (Male staff member)

Assessing consumer expectations at baseline was difficult, given the low levels of awareness among service users regarding consumer participation generally and the demonstration project specifically. The notable exception to this was the service where consumer representatives had already been recruited and were able to be interviewed at baseline. As the following example illustrates, initial expectations and aspirations were high:

'Well I believe that what'll achieve is, it'll achieve being able to break down communication barriers between the service providers and clients. It'll help by us having a voice and speaking up about issues. It'll help, hopefully to better the service, so that it's not so narrow-minded. It'll be able to be broader.' (Consumer)

Importantly, this optimism was coupled with a sophisticated and sensitive understanding of the role the consumer representative might conceivably play. As touched upon earlier (in the brief discussion of 'confidence'), the consumer representatives interviewed demonstrated an empathetic understanding of the institutional vulnerability of their peer population:

'To give those a voice that feel they have none, and a place to voice it on that is like them... like they come to me instead of coming to a staff member, they can come to someone who's been there and done that, even if the staff member has been there and done that it's still a bit intimidating to people... it's to advocate for them.' (Consumer)

5.1.7 Limitations and Risks

While many participants did not see any significant risks associated with consumer involvements, others did identify a range of potential risks:

'There is some risk that if people have had a negative experience then they are not going to be able to, in some situations, step back and be objective.' (Female staff member)

Other staff, particularly those supportive of the demonstration projects, expressed concerns about the 'institutionally' vulnerable and tenuous status of consumer participation. Their primary concerns were two-fold: Firstly, that should something go awry during the demonstrations then future support from higher management/external authorities for consumer participation would be withdrawn; and secondly, that the consumers themselves were particularly exposed and any such 'failures' could jeopardise consumers' investment in the project and the hard-won trust built up between service users and staff. Concerns were also identified by some staff regarding the potential negative repercussions for individual consumers who had assumed additional responsibilities during the projects; not merely in terms of possible project 'mishaps' but more generally in the advent of unintended consequences, such as those outlined below.

Some consumers were concerned that consumer representative roles could produce conflict and mistrust among users:

'Jealously and just spitefulness, and lies and power of people: "I want that job, I can do that job." All the bad side of the consumer could come out. But there would be a lot of good stuff too.' (Male consumer)

To some extent such fears were borne out during baseline interviews held at the service where consumer representatives had already been recruited:

'Sort of outcasting me because I'm a so-called worker. Some people were saying "she's a worker now"... It was weird. It was almost like going against the whole aim, in trying to keep it sort of, peers working with peers. A lot of them were seeing me as not a peer any more, one of them.' (Consumer)

It is important to acknowledge that for some staff the 'risks' identified with consumer participation were associated with what they believed to be a possible threat to their role as 'staff members'. Both the following examples cite staff speculating about the fears of their colleagues:

'... if they [staff] don't think it [consumer participation] is a good idea because may... maybe it's a power thing. They feel they... some staff feel there should be more power than clients...' (Female staff member)

'... it's quite intimidating to think that members of that client group are going to have access to us at a level where they're not on the other side of a counter.' (Male staff member)

5.1.8 Power and Consumer Participation

Participants were asked to consider the issue of power dynamics and its potential impact on achieving consumer participation. In some cases staff challenged the idea that there was an imbalance. For example, some staff in a residential therapeutic community cited the fact that people were voluntary and free to leave at any time as evidence of shared power. Some staff in other services were uncomfortable with the question as they felt it ignored the strong personal relationships they had with consumers.

Others were aware of this issue and sought to balance it through communication and being clear and honest with consumers. For example, alerting a consumer prior to mandatory reporting:

'Look, I suppose that the rules are set out fairly thoroughly and people are aware that there is a framework and there are guidelines, and there rules. And if they were really informed about that and aware of reporting requirements... I think if there is clarity from the beginning and people know that there are certain procedures that are implemented and have to be followed then it should be possible.' (Female staff member)

While some consumers were less certain that issues of trust and power could be readily overcome, at least one elected consumer representative reported this transformation:

'I mean, I've noticed with me, like I feel like I'm more — I'm like one of them [staff]... I've changed my way but my perspective of staff has changed a bit, but not for the bad, like I have a bit more respect for their position now. I know what I'm going to be doing.' (Consumer)

Perhaps the most apposite reflection on the merits of consumer participation vis-a-vis 'power' was the following made by a senior staff member:

'... right across the board I think the benefit is that people [consumers] might well see that the service is theirs and that they have an ability to speak about what they need... Then the service gets feedback about things that you [staff] don't necessarily see yourself and the process of that, if it works successfully, is empowering.' (Male staff member)

What is important here is the recognition that 'power' and 'empowerment' do not have to exist as phenomena that one 'side' or group possesses at the expense of another. That, in fact, the empowerment of consumers does not necessitate the disempowerment of staff but rather may contribute to the betterment of both groups in co-existence.

This is a central issue if consumer participation is to develop successfully in the drug treatment context and will therefore be explored further in the follow-up analysis and in the final report.

5.2 Evaluation Findings

Evaluation interviews were conducted with staff and consumers of the five participating sites in the months following the baseline interviews. The primary aim of these interviews was to explore and record the impact of the demonstration projects, from both consumer and staff perspectives. The following section details the findings under a number of organising themes: awareness, understanding, interest and valuing in consumer participation; stability; who is a consumer; sustainability; expectations – project, consumer representative; power and empowerment.

Prior to addressing the findings proper, it is worth briefly revisiting the breakdown by service type of the five participating agencies. A brief overview of each demonstration project has also been included. These overviews have been written using primarily data from the staff interviews augmented with that from consumer interviews. To ensure the independence of the evaluation and the confidentiality of participating services and service consumers, the names and identifying details of the services have been withheld.

Pharmacotherapy:

- A metropolitan, government-operated pharmacotherapy service:
The aim of the demonstration project was to recruit, train and notionally employ two services users as consumer representatives. The role of the consumer representative was envisaged to provide both support and advice to peers on the pharmacotherapy program, particularly those new to the service. As part of the recruitment process, the local drug user organisation was invited to run training and education sessions for both staff and consumers; subsequently the two representative positions were filled. It was at this juncture – just prior to the consumer representative’s deployment on ‘the floor’ – that the project stalled. The primary explanation offered subsequently by staff interviewees was the high turnover of staff, particularly the key contact staff member. The protracted delay that followed included the late remuneration of the two representatives. At the point of evaluation, the key contact had returned to the service and efforts were underway to revitalise the project and, most especially, the flagging enthusiasm of the consumer representatives.
- An inner-metropolitan, non-government, primary health-care service model:
Here the aim of the demonstration project was two-fold: Firstly, to garner feedback from consumers concerning the service’s recent move into new premises, especially the co-location of the needle syringe program with the primary health-care unit; and secondly, to organise a consumer-driven review of the existing ‘Client Rights and Responsibilities Charter’. A well-known, long-term service user was approached directly by key staff and appointed (discretely) as the consumer representative. A questionnaire was drafted by the project’s key staff member, with input from the local drug user organisation, and reviewed widely by staff. This instrument was then administered by the consumer representative to those consumers willing to participate. At the point of evaluation a short report had been tabled by the key staff member using de-identified material from the questionnaire. The second part of the project was yet to be completed.
- A regional, non-government, community-based service model:
There were three aims of the demonstration project: Appointing a consumer representative; reviewing policies and procedures; and running a series of regular focus groups with consumers. It is important to note, however, that the consumer consultant did not identify as having any current

drug treatment experience but did have other 'consumer' experience. At the point of evaluation, the service had only recently appointed the consumer consultant and the other outcomes had not been achieved. The manager of the drug and alcohol team, however, remained committed to the project and it was intended that the consumer consultant would continue reviewing policies and procedures and, with the help of a staff member, commence running the focus groups. At this juncture, concerns were noted regarding the apparent disengagement of both consumers and staff from the project. It was hoped that the appointment of the consumer consultant would begin to address at least the former.

Detoxification:

- An outer-metropolitan, government-operated, multi-disciplinary service model:

The principal aim of the demonstration project was to 'legitimise the voice of the consumer' via the establishment of a 'consumer participation council'. The 'amazing reluctance' to get involved, even among supportive staff, coupled with misunderstanding (even resistance) from other staff, resulted in little progress at the point of evaluation. The notion of a 'consumer council' was already a concession to those staff concerned about higher levels of consumer participation (such as the involvement of consumers in staff recruitment etc.). Nonetheless, the service director remained committed to the concept of consumer participation and a long-term goal of having a consumer representative on the payroll. In practical terms, a steering committee, comprising partner agencies (including the local drug user organisation), had been established and the terms of reference and job description for the 'lead' consumer councillor had been completed.

Residential rehabilitation:

- Based on a therapeutic community model:

The broad aim of the demonstration project was to better meet the needs of service consumers via increasing their levels of participation. At the point of evaluation, staff fed back three key achievements: Increased levels of consumer feedback sought (and received) across all stages of the program; the establishment of a 'formal' meeting held once a week between management and senior residents; and lastly, the establishment of a 'consumer reference group' that met fortnightly and was drafting a questionnaire regarding staff training needs. Staff of the therapeutic community reported very positively on the progress and outcomes of the demonstration project. This was commonly at odds with data from consumer interviews — a point of discussion addressed later in the report.

5.2.1 Awareness, Understanding, Interest and Valuing in Consumer Participation

Baseline interviews with service consumers noted a limited awareness of the term 'consumer participation'. The introduction of the demonstration projects made limited, if negligible, impact on general levels of consumer awareness — both in terms of their knowledge of the actual demonstration projects or the concept of consumer participation generally. The clear exception was in those instances where consumer representative positions had been created as part of the demonstration project and the consumers fulfilling these roles were able to be interviewed. Those services that engaged drug user organisations to deliver tailored education and training appeared to foster a better understanding of consumer participation among service users than those that did not.

As noted in the baseline findings, staff were more likely than consumers to be familiar with the term 'consumer participation', even if they had had no practical experience of consumer participation in a drug treatment setting. With regards to an awareness of the demonstration project itself, staff interviewed in the evaluation stage exhibited a range of understanding and interest. While individual staff differences — such as their employment status as casual or part-time — may be partially responsible for the disparity in levels of knowledge, a further explanation may lie with the developmental histories of the demonstration projects. In some instances, projects had been developed in relative isolation, with only a manager or several interested staff involved, and with little communication more broadly among staff. It is worth noting that the model of consumer participation promoted in the TSU Project: Phase Two shows the importance of involving staff and consumers from the outset. However, in practice, none of the services consulted or included consumers in the development or writing of the project proposals, or in later activities such as writing the position description of the consumer representative or, even when consumers were actively involved, reviewing and revising the project plan. While the lack of pre-existing consumer participation may have understandably precluded consumers from early involvement in projects, it is less clear why staff should also have had such limited engagement.

The general high level of support for the concept of consumer participation among staff noted at baseline remained so during the evaluation interviews. As both the following examples illustrate, for some staff the notion of consumer participation was a matter of principle:

'It is actually part of our organisational ethos that we're a community health centre so you can't call yourself "community" if you don't have community involvement.' (Male staff member)

'Our clients are the experts in their own lives and, you know, we've gotta listen to them... And it's not a matter of we're the experts sitting here on our high and lofty mountain looking down on people, you know. It's about people. And they're actually the experts in their own life. And if we don't work with them then we're, I feel, then we're not, we're not doing what we're supposed to do.' (Male staff member)

Nonetheless, staff support for consumer participation was neither uniform nor unproblematic. As one senior staff member explained, there was still an attitude of 'I don't like this', 'I don't want this' (male staff) among some staff. While another service manager noted that he anticipated some staff to 'white-ant' the demonstration process and had put in place contingency plans for strong staff opposition to the consumer participation project (male staff). The attitude of staff towards the demonstration project — specifically the notion of consumer participation — was an issue of concern for some of the staff interviewed. As one staff member explained, when introducing the concept of consumer participation, one must 'tread very carefully', particularly when dealing with a large cross-section of staff (male staff). Indeed, this same staff member went on to suggest that the greatest barrier to the project succeeding was 'us — the staff'. So while none of the staff interviewed actually expressed any opposition to the concept or implementation of consumer participation, they were nonetheless aware of antipathy among members of their team.

Levels of awareness and/or understanding of consumer participation remained universally low among consumers. Moreover, and more alarmingly, knowledge of their services' demonstration projects was equally poor. Consumer interviewees were frequently unfamiliar with the subject matter of their interview and commonly required prompting by staff prior to interview. The type of service, the state of project progress, and the particular consumers interviewed were all influential in shaping responses to

questions of interest and belief in consumer participation. The role of service type will be addressed in detail elsewhere in the report but, generally speaking, consumers of the residential rehabilitation and detoxification services appeared to exhibit relatively less belief in their capacity to participate — that, indeed, having input into the running of a service was typically considered a ‘staff job’. As with staff, the level of project progression clearly contributed to levels of awareness and understanding of consumer participation among service users.

There appeared to be a correlation between the extent of project progress and the level of awareness and knowledge demonstrated among consumers at interview. As noted earlier, this was also evident where drug user organisations had provided education and training sessions as part of the demonstration projects’ implementation. Finally, there was a clear relationship between levels of consumer understanding and their level of involvement (or otherwise) in the demonstration project. Unfortunately, interviews with ‘appropriate’ (i.e. involved) consumers could not always be arranged, suggesting a limited involvement of consumers in the demonstration project and/or a limited relationship between services and consumers.

Having remained unobserved or unremarked upon during baseline interviews but evident during evaluation, was varying degrees of consumer cynicism regarding staff motives for promoting consumer participation. Some service users indicated the involvement of consumers in service evaluations appeared tokenistic at times — that staff would seek out what consumers wanted but not put it into action. Some consumers were critical of what they considered to be bias in the manner in which consumers were recruited to provide service feedback, suggesting services’ attempts to tailor responses. The following examples are illustrative:

‘They are very picky in this place sometimes, like who they pull out... that’s a lot of what goes on here, it’s just fuckin’ feathering of the nest in the extreme.’ (Male consumer)

‘They are very careful about who gets to say what.’ (Male consumer)

‘They tend to, with things like this, they let certain people know... who would be good for it.’ (Male consumer)

What remained a strong theme during evaluation interviews, as during the baseline interviews, was a conviction among consumers in the value of ‘lived experience’. The latter was invariably coupled with and judged superior to what might be euphemistically termed ‘textbook learning’. The following are illustrative:

‘You can’t learn that stuff from a textbook.’ (Male consumer)

‘My experience tells me that only an addict knows an addict.’ (Male consumer)

This seems to suggest that while considerable skepticism, if not explicit cynicism, exists among consumers towards a service’s commitment to genuine consumer participation, there was nonetheless a privileging of consumers’ knowledge (as ‘lived experience’) over that of a textbook variety commonly attributed to staff.

5.2.2 Stability

Among both staff and consumers interviewed at baseline, the subject of ‘stability’ was interpreted

exclusively as a question of consumers' suitability for roles as representatives or advocates. While at baseline the definition of 'stability' was somewhat fluid — in so far as its definition changed across service type, invariably reflecting the service's treatment ethos (typically 'abstinence' or 'harm reduction') — it was nonetheless used and understood as an attribution belonging to individuals. During baseline interviews the range of views regarding stability was similar among both staff and consumers, including among those individuals identifying as current 'users'.

In evaluation interviews the term 'stability' was again employed to describe an individual's status, with a number of consumers stating that many consumers were simply too 'unstable' to assume responsibility within the organisation. However, what also became apparent during evaluation was the question of service stability: Was the service itself fit for duty? The lack of stability of staff and the concomitant lack of organisational memory was a predominant feature of evaluation interviews, particularly among service staff. All five participating sites experienced considerable delays and disruptions with their projects. One service's project that had initially exhibited promise was effectively left 'feel[ing] like a rudderless ship' in the aftermath of continual staff changes; or as the interviewees remarked:

'And I have to be perfectly honest here, it's not gone smoothly... We've had a succession of people being the prime mover and as people leave, [are]seconded, lose interest, that sort of thing... We've had many, many hands being, being the prime person.' (Male staff member)

'I think a handover would have saved us five months of stuffing around.' (Female staff member)

While there was divided opinion as to the need for a paid, dedicated staff position solely responsible for the promotion of consumer participation, there was universal support for the need for stability of key staff during the project, including — as a minimum — a designated and recognised 'contact person'. One service advocated having few staff directly involved in the demonstration:

'Easier to have less people, keep it simple.' (Male staff member)

Nonetheless, opportunities were afforded all staff to contribute. This same service emphasised the importance of having not only a 'stable' management team during the demonstration but a 'stable and experienced' staff, ideally one with a history of, and familiarity with, consumer participation.

The term 'core' was one commonly deployed by staff interviewees to describe service 'business' that was deemed essential as opposed to matters considered marginal or 'non-essential'. In at least one service the demonstration project was considered to have suffered because of its 'non-core' status. As one staff member explained:

'And I guess at times the, just the workload... in the whole centre meant that the consumer rep project wasn't getting the, the time and input that it required.' (Male staff member)

In this instance it was felt that the absence of 'core' status meant that while the 'lofty ambitions' of the demonstration was laudable, it was neither well-planned nor adequately resourced. Furthermore, it was stressed by this interviewee that this lack of attention to the project was compounded by other 'non-core' projects taken on by the service at the same time. This participant suggested that, in future, such projects be introduced one at a time, ensuring adequate resourcing, including a dedicated staff member to promote sufficient and sustained focus.

An analysis of the broader, public health and socio-economic context within which these individual

services operate, and within which the demonstrations were introduced, lie outside this report. Nonetheless, it is worth noting that several senior staff emphasised the pressures of a 'system' that placed ever greater demands on services and staff with little or no provision of additional resources; or, indeed, the role of 'decision makers' who are not always aware of the particular constraints operating within individual workplaces.

5.2.3 Who is a consumer?

Not unlike the concept of 'stability', the term 'consumer' was somewhat free-floating in its application, tending to reflect both individual and contextual variations. The term took on different meanings within different types of treatment. Many users of residential rehabilitation or detoxification services considered all ex-users to be 'consumers'. Alternatively, some consumers receiving opiate substitution therapy believed ex-users to be too far removed from the drug-using community and therefore unrepresentative of 'consumers'. In the context of consumer participation they believed such ex-users had the potential to do more harm than good as 'they think they are better than us' (consumer).

It was noted during interviews and visits to services that, in some instances, a high proportion of staff identified as past drug users. In one service, for example, it was reported that anecdotally up to 70% of staff were 'ex-users'. The vexing question of when a 'consumer' becomes an 'ex-user' remains an important, if unresolved, one. It is of central importance precisely because the TSU Project has been founded on a division between those who provide and those who consume services. Are, for example, some staff of the aforementioned service to be considered 'consumers' — and, by extension, others not?

In another service the team leader mooted possible concerns about staff 'allegiances' when discussing several young team members he identified as having their own drug- using histories. These staff were also considered by their team leader to be the most vocal and committed advocates of consumer participation. Such staff have invariably been employed on the basis of their professional qualifications and not as a result of their personal history, yet are sometimes still identified on the basis of the latter. This raises important conceptual and practical questions concerning self-other identity making: blurring what has been constructed as an absolute distinction between staff and consumer.

5.2.4 Who Should Represent Treatment Consumers?

One unexpected issue that arose in interviews with consumers in both residential rehabilitation and detoxification settings was the matter of discrimination between people within the same services. The TSU Project: Phase One excluded services (and, by extension, the consumers of those services) that provided treatment for alcohol use only. As the TSU Project: Phase Two was focused on evaluation of a series of demonstration projects in a realist framework, it was not feasible or appropriate to exclude consumers on the basis of whether they were being treated for alcohol or illicit drug use issues. A number of the services involved in the demonstration projects provided a 'mix' of services for both licit and illicit drug use issues and therefore projects were open to all service consumers. Although the majority of consumers interviewed at baseline and evaluation were illicit drug treatment consumers, others were accessing the service for either licit or a combination of licit and illicit drug use issues. For other services, such as pharmacotherapy, it should be noted that some consumers are managing issues associated with the use of multiple substances.

At baseline and evaluation a number of consumers talked of the differences between their own drug use and that of others, the primary differences being 'drug choice'. On separate occasions, service consumers receiving treatment for alcohol use expressed a very clear distinction between the use of alcohol and what they deemed as 'drug' use, which for them was illicit drug use only. In one instance a consumer stated he didn't like 'chemical users' for a number of reasons including negative perceptions of illicit drug users being nasty, selfish, untrustworthy, and unable to stick to the rules, such as bringing drugs into the service, unable to socialise with others, etc. Following these comments, the interviewer questioned how such views (that 'alcohol' users were perceived to be of a better calibre or more suitable for certain roles than those in treatment for illicit 'drug' use) might be managed in relation to consumer participation in a service that provides treatment for both alcohol and other drug dependence? In particular, could one person represent both groups if there were different needs for different consumers? The consumer stated in response that he thought it would be best for different groups of consumers (based on drug of choice) to be represented separately.

5.2.5 Sustainability

The question of sustainability, with regards to consumer participation, is a complex and multi-faceted one. What follows is necessarily only an overview of several key issues.

Higher/external management:

The role of higher management, such as area health services or executives of community health boards, were cited as crucial for both the short- and long-term success of consumer participation. Without their imprimatur, service provider participants considered current or future consumer initiatives were unlikely to be introduced or sustained. The presence of external structures required careful consideration and negotiation, along with a recognition of potential limitations. Policies such as those governing the payment of consumer representatives, mandatory police checks for employees, and the placement of volunteers were three examples cited. Conversely, the presence of supportive senior management acted as a facilitator, as the following example illustrates:

'... having a supportive management structure was really important — really important. And it gave us the confidence to do this.' (Male staff member)

Experience:

Feedback from evaluation interviews suggested that the small successes experienced during demonstration projects were instrumental in building the confidence and the belief to attempt further initiatives. The following description from a residential rehabilitation staff member captures the enthusiasm and momentum that can follow consumers' participation:

'It's magic really... just incredible seeing people's confidence build as they're given more and more responsibility. And they are actually stepping up to the mark.' (Female staff member)

The benefits of consumer participation were not limited to consumers but were also noted among service providers, particularly those who had previous positive experiences of consumer participation. Some staff with backgrounds in mental health brought with them valuable training and experience in consumer participation. For some staff these earlier experiences had proven formative in their ongoing approach to service provision and consumer work.

5.2.6 Expectations — Project, Consumer Representative

Given the low levels of awareness among consumers of either consumer participation as a concept or its application via the demonstration projects, it is difficult to comment generally on the expectations of consumers. Of those consumers who were interviewed at evaluation most had little to no expectations. A notable exception was among those consumers who became consumer representatives during the course of their service's demonstration project. Among this small cohort the expectations were high at baseline, as the following example illustrates:

'... what I'm hoping it will achieve is a common ground for staff and consumers to work out things, like you know, how do you put it in to words? It's like an even plane so everyone's on the same level, everyone's the same, like no-one's better than anyone, no-one's — even though this person works here and you're a consumer, you both got the same rights and you're both equal. You don't have to sit there, you know put your head down and think "Oh they're the staff I can't say anything what if they take my kids? What if they do this? What if they do that?" you know.'
(Consumer)

In this instance, despite a promising start — including the active utilisation of the local drug user organisation and a carefully crafted consumer representative selection process — the demonstration stalled at the point of real possibility. The reasons for this were varied — principally the high turnover of key staff — but one consequence for the consumer representatives was the service's protracted delay in remunerating them. This failure, itself a symptom of broader failures, understandably resulted in the diminished enthusiasm, motivation and trust of the two consumer representatives affected.

One senior staff member expressed his 'annoyance' at what he considered to be the lack of adequate support or resources made available to undertake the service's demonstration properly. This had resulted in what he saw as the 'unfair' treatment of consumer representatives — 'playing with people's emotions', their sense of self-worth and trust in the organisation:

'I'm thinking of one consumer rep in particular [who] was taken on board as a life-changing experience... to have responsibility, to have input, to be able to give back to a service...' (Male staff member)

Alongside the limited outcomes described above were also positive reports of some services' reinvigorated commitment to the principle and practice of consumer participation as a result of the demonstration project; of high expectations for the future. One staff member described what she believed to be the effect of the project:

'It's reinforced what we do but I think, more importantly, the "why" we do it. It's not just habitual. But it's made us revisit the, the rationale. It's been very, very useful; professional practice-wise it's been very useful.' (Female staff member)

The same optimism is also present in the staff member's description of consumers' participation:

'The absolute goodwill and enthusiasm, dedication and commitment from all the consumers... consumers have been the stars of this project.' (Male staff member)

Similarly, a senior staff member of another service suggested the outcome of the demonstration project had been to reinforce the value of consumer participation and the service's confidence in it, auguring well for its future development and expansion.

Finally, the position of consumer representative, introduced as the key constituent of several demonstration projects, warrants mention within this discussion of expectations. The position of consumer representative was challenging, if not also rewarding, for the individuals appointed. The position of consumer representative was subject to not only occasions of jealousy and mistrust from fellow service users, but burdened too by their inappropriate and sometimes onerous expectations. The risk for consumer representatives was exposure to a level and type of demand that was often unrealistic and inappropriate. As this consumer representative foresaw at baseline:

'[Service users] want [methadone takeaways] and they won't be able to get them because it's just government policy, and we can't change that, even as consumer reps. Even as staff they can't change that, so...' (Consumer)

It was as a result of such demands that services focused considerable attention on publicly clarifying the role of the consumer representative and enacting appropriate forms of support and supervision for the position. In several cases the latter involved ensuring external supervision was available from the local drug user organisation in addition to internal staff support.

5.2.7 Power and Empowerment

The themes of power and empowerment remain a defining issue if consumer participation is to be successfully developed in the drug treatment context. The following brief discussion of power and empowerment will focus on the position of consumer representative, drawing on comments and observations made in the course of the evaluation interviews. While obviously other expressions of power were at play during the demonstration projects, such as the higher management of area health authorities discussed earlier, these will be explored in a more general and in-depth exploration of power and empowerment canvassed later in the report.

The position of consumer representative provides an elucidating illustration of the complex and, at times, blurry nature of power and empowerment within the context of consumer participation in drug treatment. On one hand the consumer representative appears to occupy a position of increased power (and empowerment) relative to their peers. Indeed, it can be understood as a promotion, even attracting jealousy from others. On the other hand, what power can be said to accrue to the position of consumer representative is only so if permitted by staff; the reigns must be loosened by those ordinarily holding them. This 'letting go' of control was, in turn, described by one senior staff as a 'challenge' that was 'complex and layered'.

In one service, staff reported witnessing the personal empowerment (growth in confidence etc) that accompanied a consumer's appointment as a consumer representative, while within another service a staff member bemoaned the 'playing with people's emotions' (the 'disempowerment') that resulted when the consumer representative positions were not appropriately remunerated nor properly exercised. Paradoxically, the position of consumer representative can only be effective if the individual is still recognised as a 'peer' by the consumer group. Coming to be identified as 'one of them' (a staff member) effectively robs the position of credibility, and therefore power, among its constituents. (A hypothetical variation on this theme was mooted by interviewees and might be termed the 'yes man': effectively an overly compliant peer chosen by staff to act as a token consumer representative.) In both instances it seems that the 'voice' of the representative must remain identifiably 'ours' to consumers in order to remain authentic and empowered — as 'us' and not 'them'. Yet this in turn appears to draw

upon and reinforce the very dichotomy (of staff versus consumer) that consumer participation purports to challenge. Consumer participation may work best when these distinctions are appreciated in positive and collaborative terms.

5.3 Summary

Levels of awareness and understanding of consumer participation exhibited among service users across all five sites remained universally low throughout the project. A clear exception was apparent in those instances where consumer representative positions had been created as part of the demonstration project and the consumers fulfilling these roles were able to be interviewed. Importantly, the data suggests that most consumers did value the concept in principle once it had been adequately explained. Staff were generally more likely than consumers to be familiar with the term 'consumer participation' (albeit most without any professional experience) and broadly supportive of it. Aside from a minority of staff that remained consistently disinterested, opposition among staff appeared most vociferous when higher forms of consumer participation (such as staff recruitment or appraisals) were mooted.

The terms 'stability', 'ex-users', and even 'consumers', prompted a number of important conceptual and practical questions. The notion of 'stability', initially considered a 'positive' attribution of individuals, became a means to assess the suitability of services. The readiness of individuals to take on the responsibilities of consumer participation became a concern about the fitness of services to run the project. Not unlike 'stability', the terms 'ex-user' and 'consumer' have become normalised within the taxonomy of drug and alcohol practice and policy. However, like 'stability', these terms are neither neutral nor fixed: their meaning and application varied across treatment settings and between speakers, from senior staff to consumers. The fluidity (and power) of these terms need to be recognised in the context of this project where each carried considerable currency.

Expectations of the project remained low to non-existent among consumers due to universally poor levels of awareness. The exception, as noted above, was among those consumers interviewed who had been recruited as representatives. Staff were mixed in their aspirations for the long-term benefits of consumer participation. In the service where consumer representatives and staff had been the most vociferous in their initial expectations there was the most dejection, frustration and cynicism reported at evaluation (for reasons of project discontinuity, failed consumer representative remuneration etc). This 'failure' merely highlights the institutional vulnerability of consumer participation in its nascent stages and, most particularly, of those consumers who were drawn into the process in good faith only to be 'let down' by the very service which encouraged their involvement.

By way of explanation for the lack of progress with the demonstration project, several senior staff made explicit mention of their over-stretched, under-resourced service. It is also important to emphasise how services also consistently acknowledged they had underestimated the amount of work involved in implementing the demonstration projects. Here a parallel could be drawn between staff's baseline belief (in evidence across most services) that they did not require any specific training or education vis-a-vis consumer participation and services as a whole, being somewhat underprepared in their approach to the demonstration project. Careful consideration and planning needs to take place in future before services take on the complexities incumbent in consumer participation in this context.