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Beyond recruitment? Participatory online research with people who use drugs

ABSTRACT

The use of the Internet by people who use drugs presents an opportunity for researchers not only to successfully recruit drug users to participate in research, but to go further and engage drug users more fully in dialogue. In this paper, we present data arising from a doctoral research project which examines drug use in an Internet society by focusing on the experiences of participants in online dance music and drug discussion forums, and we examine the ethical issues and problems that arose in this context due to the illegal and stigmatised status of drug use. We chose to engage with forum moderators and users instead of treating public Internet forums as freely available "data." Successes and failures that occurred during this process are outlined, and we discuss what was involved in maintaining the discussion threads once they were accepted and supported by group moderators. Issues that arose in attempting to continue engagement beyond recruitment are also discussed. To conclude the paper, we evaluate our efforts to conduct participatory online research and suggest how other researchers investigating illegal and/or stigmatised behaviours may build on our work.

INTRODUCTION

While Internet surveys and online recruitment notices have become more commonly employed in drug use research (Miller & Sønderlund, 2010), the potential for interactive, online engagement with people who use drugs has received comparatively little attention. In this paper, we describe the recruitment and engagement of a sample of young Australian participants in online discussion forums who were users of psychostimulant and hallucinogenic drugs and reflect upon the ethical issues that arose during this process. Our aim here is to stimulate discussion about how researchers can engage more closely with people who use drugs, who are often asked to contribute to research but less often given further opportunities to be involved in the research process. Furthermore, people who use illicit drugs may be at risk of experiencing a range of possible legal and social harms as a consequence of both discussing illegal behaviour in public online forums and the publicity associated with the dissemination of research findings. We therefore see drug users as an important sentinel group for looking at ethical matters in online research, and believe our experiences can also inform ethical practices in research exploring other online communities characterised by illegal, stigmatised and/or hidden behaviours.

Participant involvement in research through the Internet

Within the positivist paradigm that once dominated social research, researchers controlled the research process by determining research questions, methods, results, and conclusions, while the role of research subject was

narrowly defined. Over the last two decades, alternative ways of conceptualising the relationship between researcher and participant have emerged (Christians, 2005; Fry et al., 2005; Petras & Porpora, 1993), and medical researchers employ a more participatory discourse—research "subjects" are now "participants" (Boynton, 1998). Wider and more meaningful participant involvement or "consumer participation" in health and medical research has been advocated in Australia (National Health and Medical Research Council, 2002, 2004) and in the United Kingdom (see Boote et al., 2002). However, meaningful participant involvement in drugs research requires that participants publicly identify themselves as current or former drug users and have access to sufficient support and resources to enable participation. These pre-conditions act as barriers for people who use illegal drugs who desire greater input into research (Rowe, 2004; Singer, 2006). Although there are challenges to meaningfully engaging people who use drugs in research, the importance of doing so has been emphasised by peak bodies representing the Australian alcohol and other drug sector (Fry, 2007a, 2007b) and drug user organisations (Australian Injecting and Illicit Drug Users League, 2003). Successful partnerships between young people who inject drugs and researchers have also been demonstrated (e.g., Coupland et al., 2005).

Alongside increased advocacy for participant involvement in research, the Internet has become ubiquitous in everyday life (Fuchs, 2008) and, unsurprisingly, the Internet increasingly plays a key role in facilitating the research process (see Fielding et al., 2008). One of the benefits of using the Internet for research is how online communication can positively influence the researcher–participant relationship. Lack of physical presence and separate physical settings all reduce control and power of the researcher, potentially leading to a more balanced power relationship between researcher and participant (Hewson, 2007; Illingworth, 2001; Seymour, 2001). Furthermore, the lack of physical presence of the researcher makes it easier for the participant to withdraw or opt out (Kazmer & Xie, 2008). Allen (1996) was one of the first researchers to advocate utilising these characteristics of online communication to maintain a dialogue within which the parameters of the research project are negotiated and renegotiated over time. Online discussion groups provide this opportunity where participants can "talk back" at their convenience without revealing their full identity (Bakardjieva & Feenberg, 2001). Researchers posting a request for participation to an online group are not only advertising their project, but are also inviting an online dialogue with the group of both the topic and the project itself. This may work in favour or against the researcher's interests, but either way, the resulting dialogue may disrupt the researcher's attempts to control researcher–participant communication (Bakardjieva & Feenberg, 2001; Brownlow & O'Dell, 2002).

Online recruitment and engagement in non-drug-related research

Health researchers, mainly targeting online support groups to attract users with specific health problems, have reflected on the opportunities and challenges of accessing and engaging with research participants through online discussion groups (Illingworth, 2001; Im et al., 2007; Koo & Skinner, 2005; Mendelson, 2007). Their experiences demonstrate the importance of successfully engaging with website moderators or gatekeepers (also see Murray & Sixsmith, 1998; Smith & Leigh, 1997). Without this support, messages are more likely to be viewed

as intrusive or as "spam" resulting either in deletion or being ignored or dismissed (Im et al., 2007; Koo & Skinner, 2005; Mendelson, 2007). It is critical, therefore, to form partnerships with online community moderators by not only asking their permission to post the request, but eliciting their feedback and support as well (Mendelson, 2007). Smith and Leigh (1997) note that recruitment notices need to contain more than the typical flyers or advertisements used for newspaper advertisements. Mentioning the approval of moderators is important for establishing authenticity, and so is providing detailed information about the study and how to contact the researchers and ethics committee. Establishing trust with the forum moderators, and subsequently the forum users, involves the researcher demonstrating both technical and cultural competence within the online setting (Illingworth, 2001). These processes also reflect best practice in non-Internet-based research (Sixsmith et al., 2003).

Notions of privacy also need consideration when engaging with an online group for the purposes of research. Should the participating online group(s) be named in subsequent publications or anonymised? While the public/private status of an Internet forum may appear to be easily determined by how easy it is to access the site, the degree of privacy people experience in a specific online context depends on their *perceptions* (Sveningsson Elm, 2008). It is not necessarily the case that an online environment thought to be public by the researcher would also be perceived that way by the users themselves. For instance, while many studies are conducted using the text of public online forums or newsgroups as data without the knowledge of group members (e.g., Brotsky & Giles, 2007; Finn, 1999; Schneider, 2003, etc.), some Internet group members report a breach of trust and/or privacy when they have become aware of the research conducted using their words without their consent (King, 1996; see also Whitty, 2004, pp. 209-210). While some researchers believe anonymising group names will protect the researched group, if the material is publicly indexed and direct quotations have been reproduced, research publications can lead straight back to the group and author's name (Bromseth, 2002; Eysenbach & Till, 2001). Within the discourse of the human subjects research model (as discussed by Bassett & O'Riordan, 2002), groups as well as individuals are treated as requiring protection from potential harms associated with being identified with a stigmatised behaviour. An alternative perspective is provided by Bruckman (2002), who argues that when online discussion participants are viewed as amateur artists or writers rather than as human research subjects, anonymising them denies them credit for their creative work. The "amateur artist" perspective could also apply to the decision to anonymise participating online groups for their protection when they may wish to be credited publicly as contributors or research partners. Tensions between the human subjects and amateur artists models of Internet research became relevant during our research and are explored later in this paper.

Online engagement with people who use drugs

In contrast to this literature, except for Measham and Moore's recent work (2009), there has been scant discussion about the opportunity to engage with researched populations within alcohol and other drug research

using the Internet and the ethical issues associated with such engagement. We reviewed a selection of studies where Internet message board recruitment of drug users occurred in Australia (Allott & Redman, 2006; Black et al., 2008; Duff, 2005; Duff et al., 2007; Gascoigne et al., 2004; Mallick et al., 2007; Miller et al., 2007; Shearer et al., 2007) and internationally (Butler & Sheridan, 2007; Dalgarno, 2007; Gamma et al., 2005; Hall & Tidwell, 2003; Hough et al., 2003; Katz et al., 2008; Murguía & Tackett-Gibson, 2007; Rodgers et al., 2006; Rodgers et al., 2003; Stetina et al., 2008; Sumnall et al., 2008; Warburton et al., 2005).[1] The methods sections of these reports and papers were largely void of any detail about the process of posting recruitment messages to Internet message boards. Mostly, researchers wrote about online discussion group postings as "advertisements" or "notices." Some researchers mentioned engaging with website moderators and gaining their permission and support before posting their recruitment request (Gamma et al., 2005; Hough et al., 2003; Katz et al., 2008; Miller et al., 2007; Murguía & Tackett-Gibson, 2007). Researchers *may* have interacted within recruitment threads, but if they did, this process was not documented in these publications. The interactive nature of forums was mentioned by Rodgers et al. (2003) when discussing potential reasons why a subgroup of respondents who were recruited to their survey through an online forum emerged as different from the remaining sample. They stated that "there was also discussion of our research on these forums, with people who had just participated posting comments about it" (p. 394). This discussion is a central feature of online forums and recruitment from them. While such discussion may produce bias in samples through influencing how people respond to surveys, it also creates an opportunity for researchers to engage with their respondents about the research project.

We have identified an absence of discussion about the interactive nature of research recruitment using online forums in the alcohol and other drug research field. In the remainder of this paper, we provide an account of interactive online recruitment and engagement arising from MB's doctoral research project, which examines drug use in an Internet society by focusing on the experiences of participants in online dance music and drug discussion forums. The research project involved identifying and investigating online forums where psychostimulant and hallucinogenic drugs were discussed by Australians, conducting a survey and interviews with forum moderators, administering a web survey that explored the use of the Internet and online forums by people who use psychostimulant and hallucinogenic drugs, and engaging a subsample of survey participants in qualitative synchronous online interviews to explore the topic in more depth.[2] We chose to engage with forum moderators and users instead of treating public forums as freely available "data." Successes and failures that occurred during this process are outlined, and we discuss what was involved in maintaining the discussion threads once they were accepted and supported by group moderators. We discuss the problems we faced when we tried to continue engagement beyond the recruitment phase: our commitment to maintaining anonymity of

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[1] It was not always obvious from the published methods sections that Internet message boards were actually used to recruit participants. In these cases, invitations to participate that were posted to Internet message boards that corresponded with the published studies were identified.

[2] Please contact the authors for more detailed description of these methods.

forum groups clashed with our aim of engaging in public online discussion about emerging research findings, due to the sensitive nature of the topic of illicit drug use. To conclude the paper, we reflect upon our experiences of conducting participatory online research and suggest how other researchers investigating illegal and/or stigmatised behaviours may build on our work.

ENGAGING WITH FORUM MODERATORS

At the start of data collection (2006), we identified online forums where drugs (especially psychostimulants and hallucinogens) were being discussed by Australians. MB's experience as a member of dance music and drug focused online forums began in 2001, so the initial list of forums included those where she was an active member and others of which she had prior knowledge. Forums were added to the list through the results of web searching, mentions of new forums made by members of known forums she was observing and within other materials such as e-newsletters from dance music promoters, and later, those mentioned by forum users who participated in the online survey. Forty eligible forums were identified: 32 were dance music forums including subtypes such as *rave* and *psytrance*,[3] four were overtly about drugs and the remaining four focused on music, lifestyle and technology. Prior to initiating contact with forum moderators, MB observed, searched, read, and coded the relevant archives of each forum to develop an understanding of the kinds of drug discussion taking place, how drug discussion was managed by moderators and other forum members, and the forum rules, especially in relation to "drug talk."

A critical part of gaining the support of moderators was whether, in their judgement, the discussion of illicit drugs that would be invited by the proposed posting of an invitation to participate in a drug-related online survey would have contravened drug discussion rules on the forum. Through the analysis of forum guidelines, moderator survey responses, and online interviews with moderators, we established that the majority of forums had explicit rules about the types of drug discussion that were permitted. Some forums claimed to prohibit all drug discussion, and a few forums had no explicit limits in place regarding drug discussion. The range of types of drug discussion that were considered unacceptable by forums included: promoting or glorifying drug use, attempting to source or supply drugs, inaccurate drug-related information, personal admissions of drug use, illegal behaviour (generally), details of events, locations, clubs or names in relation to drug use, and judgemental or stigmatising attitudes towards drug users. In addition to the restrictions on drug discussion, it was generally unclear whether posting a research recruitment thread with some relevance to the group (i.e., not indiscriminate spam) was allowed.

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[3] Forums were classified as rave forums if they used the word "rave" in their title or official description of their content, and/or if they were part of the "hard dance" scene. In contrast, many other dance music forums either had a more general clubbing focus or were aligned with other specific types of dance music, such as "psytrance" (shortening of psychedelic trance). Definitions of these different electronic dance music associated scenes are never static, however, some useful analyses of examples of such scenes are described by Gibson and Pagan (2000), Thornton (1995), Siokou (2002), and Greener and Hollands (2006).

All drug forums and many dance music forums made explicit distinctions between types of drug discussion that were allowed and prohibited in their guidelines, whereas almost all of the forums with a zero tolerance policy towards drug discussion were rave forums, and almost none of the forums with no policies towards drug discussion were focused on dance music or drugs. Given these observations, it was not surprising that moderators of rave forums were less likely to complete the moderator interview and/or agree to any further involvement in the project. Moderators from three rave forums declined to participate in the survey, citing that given their "no drug discussion" rules, drug discussion did not occur on the forums and could therefore not be discussed by them in the survey. This response occurred despite the fact that drug-related discussion had been found on their forums through the original process of determining eligibility for the study. For example, one moderator of a small rave forum declined further participation in a private message in response to the initial request:

> Id like to help you but this is a website about dancing, not taking drugs. Drugs are a major part of all forms of life and i guess this is no exception. But i dont appreciate being labeled an 'online forum by Australian ecstasy, methamphetamine and other party drug users'. This is an online forum for people who dance and want to learn how. What people want to do with drugs is their own buisness not mine, we dont encourage it or tolerate it on here.[4]

In the case of most online forums whose main focus was electronic dance music, it was important not to give the impression that we expected everyone who used the forum was a drug user, as this attitude would perpetuate the stereotype that "all ravers (ab)use drugs." Rave forum members appeared especially sensitive to this possible stereotyping, perhaps due to mass media representations. The negative reaction of the rave forum moderator quoted above shows how important the wording of the invitation can be. While the text of the invitation did not, in fact, contain such a label (the sentence quoted read: "I have just begun my research project into how the use of online forums by Australian ecstasy, methamphetamine and other party drug users influences drug use practices in ways that decrease or increase drug-related harm"), this sentence was too close to labelling this moderator's forum as a "forum of drug users."

Another important issue was how best to deal with anonymity of online forum members and groups. Both the public or private context of the online environment and the sensitivity of the information or content of the data (Ess & Association of Internet Researchers Ethics Committee, 2002; McKee & Porter, 2008; Sveningsson, 2004) led us to only offer participation on the proviso of anonymity of forum members and groups, because naming participating online groups in research publications had the potential to harm those groups by associating them with illegal behaviours. While some researchers have provided participants with a choice by asking them whether they would like to be credited or to remain anonymous (Reid, 1996; Roberts et al., 2004; Sixsmith & Murray, 2001), this approach is not without its risks, especially in the case of discussion of higher-risk topics (Hall et al.,

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[4] Apart from the replacement of identifying information, extracts are presented verbatim; meaning they were not edited for spelling, grammar or typographical errors.

2004). During our research, conversations with one of the online forum moderators revealed that they would indeed prefer to be publicly associated and acknowledged within resulting publications:

> Actually, we *want* them to list us as a reference, and increase awareness in the research realm about our member base as a resource :)

Unfortunately, the desire for open acknowledgement of forums and their participants was unanticipated and was not possible within the ethics approval originally negotiated for the project. Although this forum did agree to participate under anonymous conditions, it was clear during this process that greater flexibility would have been useful so that ethics procedures could be renegotiated as more information about the requirements and preferences of participating groups became known.

FORUM DISCUSSIONS

Despite these challenges, the majority of forum moderators approached accepted both the invitation to participate in the survey as moderators and supported the recruitment thread within their forum for forum users. In total, 26 recruitment threads were posted after 35 forums were approached. Twenty-three of these were posted with moderator consent, while the other three were posted without consent after no reply was received to repeated requests. This was done after those forums were assessed to be of low intervention (i.e., it appeared that they were unlikely to see the post as threatening or as spam). A small proportion (5 of 35 forums) explicitly stated that they did not wish to host the thread as discussed above, although one of them offered to host a website link instead because they were more concerned about the risk of drug-related discussion than of hosting a non-interactive informational article on the topic. This opportunity was taken up and a feature article was written specifically for this site, a strategy which proved successful for recruitment. One further thread was posted by forum users mentioning the study without the researcher's invention.

Monitoring and contributing to multiple forum discussions involved a considerable time commitment from the researcher. After becoming familiar with how specific forum communities reacted to outside requests for information and research participation and liaising with forum moderators, MB posted requests for participation and closely monitored the discussion that followed. MB replied to questions and interacted within the discussions, responding both to light-hearted and more serious posts. The study, university, and researcher contact details were clearly identified and supported by the project website.[5]

These forum discussions were successful at recruitment, while also enabling dialogue about the project and the topic. According to the survey respondents, online forum discussion was the most successful strategy at bringing them to the survey: 74% reported finding out about the study through a 'thread in online forum', 19%

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[5] See http://ndri.curtin.edu.au/drugsonforums/

reported being "referred via email/though Internet," 6% "saw the link on a social networking site," and 2% were "referred by word-of-mouth (offline)."[6] The forum discussions provided an avenue for respondents to easily ask questions and make comments about the survey or the topic of online drug discussion. There was a stronger linear correlation between referrals and views (R = .587) than there was between referrals and replies (R = .360).[7] This pattern suggests that the amount of discussion in the thread is less important to successful referrals to the survey than the number of people who view the thread. While this makes intuitive sense, discussion is still critical to recruitment because forum threads are ordered by newest reply first and in a busy forum, a thread with no replies could sink below view within hours.

Another strategy we used to generate more interest in each online forum thread and to provide something of value to the forum was the "poll" function, which was available across around half of the forums encountered in this study. We chose a question from the survey to use as an anonymous poll that ran alongside the discussion thread, which read: "Overall how important has the Internet been to you in learning about drugs?" with responses "not important, somewhat important, important, very important." This feature was popular with 537 poll participants across 14 threads where polls were used. Not only do polls generate interest, they provide instant feedback to the forum user about how the whole group has voted. Including them can add more value to the thread for the forum itself (i.e., group leaders can learn about the group's opinions or behaviours) and polls such as this could also conceivably be used by researchers as data.

We offer here an analysis of one thread to provide readers with an illustration of the kind of discussion that was generated within recruitment threads. Although the online forums involved in the study were publicly accessible, drawing attention to them through this research on the sensitive topic of illicit drug use could lead to negative repercussions for the target group as a whole. We took care to keep information about specific forums general enough to disguise their identities, and we avoided direct quotations from public online discussion text if they could be used to identify their original source when entered into search engines. This particular thread was chosen because the discussion illustrates a typical range of responses and interactions, the moderators and forum users supported the study, and these quotes cannot be publicly found because this forum kept this part of the site only available to logged-in users and therefore was not publicly indexed. Without this protection, the anonymity promised to forum moderators and users could not be sustained. The forum in this example was a small local forum hosted by a rave promoter.

Of the 49 replies, 9 of them were posted by MB in response to comments and to inform forum users of the study's progress, and the remaining 40 replies were posted by 16 different usernames, assumed to represent unique forum users in this analysis. The majority of the interaction occurred between MB and 6 forum users, with

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[6] 822 valid cases; 15 missing. 810 provided only one response; 12 provided more than one.

[7] Calculated across 21 threads that were still online in April 2008.

the remaining 10 contributing 1 post each to the discussion. We performed a simple thematic analysis of forum user posts (excluding MB's posts). Over half of the 16 forum users actively involved in the thread posted comments classified as humour and/or banter (n = 9), and half (n = 8) discussed the topic of drugs and the Internet within their posts. This quoted post is a typical example of humour or banter:

> lol te drug survey ... " qeustion " What other communication methods have you used when discussing drugs in the past 6 months?" my answere . well we tried smoke signals but we just couldnt get it right ... he kept thinking i wanted a tree but i was asking for green ..... so in my opinion smoke signals are a fail

And this extract is a typical example of the more serious discussion about the Internet and drugs:

> Personally, I think having the Internet is a guide is better than nothing. Most of the information found regarding drugs is very accurate. I also think speaking to someone with first hands experience is far better than any information you'll find on the Internet (particularly with what to expect).

Three forum users mentioned the forum's drug discussion rules: with one asking another to post up her responses to the survey, and her declining due to these admissions being contrary to the rules on the forum. Two forum users posted endorsements of the research and their support for the topic itself. Two forum users also posted their interest in hearing about the results of the project. One forum user provided constructive feedback on one of the survey items, and two others posted simply to say that they had completed the survey.

Another topic that arose for two forum users was a belief that drug use is misrepresented by media and government. The extract quoted below follows MB's post that thanked forum members for their participation in the online survey. This forum user explains his/her views about why people were so enthusiastic about telling their story by participating in the research project:

> thats because (without sounding rude) drug users that dont abuse drugs are sick to shit of everything slightly drug related being portrayed in the most negative of ways. and even though this will never change.. it fucking should. raise truthful drug awareness, showing BOTH the positive and negative sides of drug use and factual information abuot drugs... dont just raise the alarms

This post shows the anger felt by some people who use drugs about how they see drug use being misrepresented in public discourse. It also illustrates how online discussions can be used to share such views with researchers who may be seen as providing a platform for different perspectives on drug use that challenge popular stereotypes.

BEYOND RECRUITMENT

Sharing findings with groups involved in research provides another avenue for strengthening participant involvement and is important from an ethical perspective (e.g., National Health and Medical Research Council, 2002). We encountered some dilemmas when we tried to provide opportunities for greater involvement of participants and forum groups in the research process after data had been collected. We had planned to return to

all discussions with preliminary findings with the participants to elicit their feedback. However, we became concerned about the public nature of the forums and how providing any data of significance about the drug use of online forum users could easily also be read and reported on by journalists or published in other contexts. Online forum content was being used in this fashion by journalists at the time. For example, during the period of data collection, a local tabloid newspaper (Myers & Drill, 2008) reported that:

> Thousands of Victorian youths are using Internet forums to trade tips on how to plan drug-fuelled benders at tomorrow's Big Day Out. Teens are using sites to advise each other how to get cocaine, marijuana and ecstasy into the music festival without detection by police sniffer dogs.

Considering the ethical issues, we decided that on balance it was better to avoid our results being the subject of a similar news story that had the capacity to precipitate negative consequences for our respondents and their peers. Potential harms to our participant group included public scrutiny on specific forums that could be identified in media reports as facilitating or encouraging drug-related activities and the risk that websites hosting forums in Australia could be shut down by authorities if seen to be supporting criminal activity. While all forums involved in this study were publicly accessible and therefore available to journalists, openly discussing emerging findings on public online forums also threatened the confidentiality of those forums whose members had contributed to the study by linking them explicitly with drug-related research.

These considerations led us to limit the online discussion of the research findings more than we had originally planned. MB updated forum threads with a brief description of the demographics of the final sample and expressions of gratitude. This process was not as engaging as was first hoped. The open discussion of emerging findings does not appear to be as problematic within other less sensitive research domains (for example, many researchers in the Internet studies field openly blog about their research, see Bruns & Jacobs, 2006). Open discussion of emerging research findings with drug users using the Internet was not realised within our project; however, it remains a goal which we believe researchers should continue to strive towards. Although open discussion of results online may provide an opportunity for drug users to have a stronger voice in debates which ultimately affect them more than others, researchers also need to be aware of the ethical dilemmas and potential risks to the community of study when conducting online research with those engaging in illegal and stigmatised behaviours such as drug use.

Although preliminary drug-related results were not posted to discussions in online forums, we created private online groups and invited individuals who had already expressed an interest in the findings for discussion of the emerging results. Motivated participants of the online forums involved in the project have had the opportunity to read and comment on emerging results in this more private forum. It may be the case that when researching illegal or stigmatised behaviours, email lists that do not use public archives, or online forums that are not indexed in search engines, may be more appropriate places for sharing preliminary findings and eliciting feedback from research participants. Issues surrounding the sharing of emerging ideas between researchers and people who use drugs in semi-private online settings require more discussion and empirical work.

Volunteering within communities that have helped researchers is another way that researchers can develop strong rapport with, and demonstrate their support of, participant groups. After data collection was complete, MB accepted an invitation to moderate a new forum on the Bluelight Internet discussion board called "Drug Studies."[8] Bluelight describes itself as an "international message board that educates the public about responsible drug use by promoting free discussion" and it has been identified and described elsewhere (e.g., Duterte et al., 2009; Fowler et al., 2007; Murguía et al., 2007). The goal of the Drug Studies forum on Bluelight is to encourage dialogue between researchers and members of the Bluelight community. Drug Studies hosts threads where researchers post invitations for people who use drugs to participate in research projects. The dissemination of findings when studies are complete is also encouraged, as is the participation of researchers in an ongoing discussion of their research. Volunteering to moderate the Drug Studies forum has provided opportunities to be involved in ongoing dialogues about research in this field, to engage with researchers from different disciplines from across the world, and to discuss drug-research-related issues with Bluelight members. While some researchers have attempted to build full partnerships with online communities of drug users like Bluelight (e.g., see Murguía et al., 2007), in our experience, the full potential of participatory online research with drug user communities has yet to be realised. More work is needed to understand and find adequate responses to the ethical complexities that occur when conducting participatory online research with drug user communities and other groups who engage in and discuss stigmatised and illegal behaviours online.

DISCUSSION

Our efforts towards conducting participatory online research with people who use drugs have demonstrated the importance of developing relationships with forum moderators and treating online recruitment using interactive technology as *interactive*. This process takes time, patience, investment, and the capacity to listen and respond to comments from the participant group. Researchers can use this opportunity not only to invite people to participate in their project, but to also engage with them about the topic, address their concerns/comments, and incorporate various drug user perspectives into their overall investigation. The potential for wider, more meaningful engagement of research participants through online communities is an especially important opportunity for stigmatised and/or hidden populations for whom the characteristics of online communication can enable a more equal relationship between participant and researcher.

We offer some initial reflections that may assist researchers who aim to both recruit and engage research participants through online discussion forums. Firstly, it is important to become familiar with the technological platform and the community to understand how the group may react to outside requests for research participation, and try to anticipate potential problems such as the content of the thread breaching forum

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[8] See http://www.bluelight.ru/vb/forumdisplay.php?f=180

guidelines. Discussions with forum moderators about the appropriateness of the proposed thread are critical. Once forum moderators have endorsed your discussion and you have introduced yourself and your study to the group, don't just treat the thread as a notice or advertisement. As the original poster, there is a general expectation that you will respond to comments and questions and offer further information. In doing so, you help keep the thread active, and you can use the opportunity to engage with the issues forum members are discussing. We found it useful to attach polls to generate further interest in the thread. We also had a project website so people who wanted more detailed information about the project could easily obtain it. It is also very important not to delete your thread or your posts just because recruitment is complete. To move beyond just recruitment, researchers need to continue discussions through all stages of the research process including the provision of results and links to final publications, although we advise that researchers consider how much of their emerging findings can be openly discussed in a public forum and consider semi-private online spaces as an alternative if there are risks to the participant group inherent in open discussion. An ongoing relationship between researchers and online discussion groups could potentially result in participant input into the initial stages of the research process and culminate in fuller partnerships between researchers and participants. The potential for full partnership with participant groups precipitates further exploration of the risks and benefits of public attribution and ownership of this role in the research process.

Our project included two quite different situations. While many forum groups would only participate in the research if their anonymity was assured, one forum group wanted to be publicly credited as a research contributor. There are tensions between the human subjects and amateur artists models of Internet research; between protecting the researched group through de-identification and recognising the researched group through public attribution. Do researchers have a duty of care to protect individuals and groups from the potential for negative publicity and self-incrimination? And if researchers do not allow such public recognition, are they denying individuals and groups the right to be identified and recognised as authors and partners? While these questions remain unanswered in our work, our experiences engaging with Internet forum groups do bring into question any assumption that public online discussions are data available for research use without the permission or consent of their authors.

Our experiences provide a starting point for researchers seeking to move beyond recruitment towards stronger engagement with people who use drugs through online discussion forums. Our work can be expanded by exploring the negotiation of closer partnerships with online groups at the initial stages of conceiving research projects and the continued engagement with online groups through semi-private or private online settings should risks be associated with public disclosure and discussions. We hope that researchers seeking to recruit research participants from Internet discussion groups may also seek to engage those groups in a broader dialogue about research agendas and policies that affect their lives.

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REFERENCES

Allen, C. (1996). What's wrong with the "golden rule"? Conundrums of conducting ethical research in cyberspace. *The Information Society, 12*, 175-187.

Allott, K., & Redman, J. (2006). Patterns of use and harm reduction practices of ecstasy users in Australia. *Drug and Alcohol Dependence, 82*, 168-176.

Australian Injecting and Illicit Drug Users League. (2003). *A national statement on ethical issues for research involving injecting/illicit drug users*. Canberra: AIVL. Available from http://www.aivl.org.au/files/EthiicalIssuesforResearchInvolvingUsers.pdf

Bakardjieva, M., & Feenberg, A. (2001). Involving the virtual subject. *Ethics and Information Technology, 2*, 233-240.

Bassett, E., H. , & O'Riordan, K. (2002). Ethics of Internet research: Contesting the human subjects research model. *Ethics and Information Technology, 4*, 233-247.

Black, E., Dunn, M., Degenhardt, L., Campbell, G., George, J., Kinner, S., et al. (2008). *Australian trends in ecstasy and related drug markets 2007: Findings from the ecstasy and related drugs reporting system (EDRS)* (Australian Drug Trends Series No. 10). Sydney: National Drug and Alcohol Research Centre, University of New South Wales.

Boote, J., Telford, R., & Cooper, C. (2002). Consumer involvement in health research: A review and research agenda. *Health Policy, 61*, 212-236.

Boynton, P. M. (1998). People should participate in, not be subjects of, research. *British Medical Journal, 317*, 1521.

Bromseth, J. C. H. (2002). Public places – public activities? Methodological approaches and ethical dilemmas in research on computer-mediated communication contexts. In A. Morrison (Ed.), *Researching ICTs in context* (pp. 33-62). Oslo, Norway: University of Oslo.

Brotsky, S. R., & Giles, D. (2007). Inside the 'pro-ana' community: A covert online participant observation. *Eating Disorders, 15*, 93-109.

Brownlow, C., & O'Dell, L. (2002). Ethical issues for qualitative research in on-line communities. *Disability and Society, 17*, 685-694.

Bruckman, A. (2002). Studying the amateur artist: A perspective on disguising data collected in human subjects research on the Internet. *Ethics and Information Technology, 4*, 217-231.

Bruns, A., & Jacobs, J. (Eds.). (2006). *Uses of blogs*. New York: Peter Lang.

Butler, R. A., & Sheridan, J. L. (2007). Highs and lows: Patterns of use, positive and negative effects of benzylpiperazine-containing party pills (BZP-party pills) amongst young people in New Zealand. *Harm Reduction Journal, 4*. Available from http://harmreductionjournal.com/content/4/1/18

Christians, C. G. (2005). Ethics and politics in qualitative research. In N. K. Denzin & V. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 139-164). London: Sage.

Coupland, H., Maher, L., Enriquez, J., Le, K., Pacheco, V., Pham, A., et al. (2005). Clients or colleagues? Reflections on the process of participatory action research with young injecting drug users. *International Journal of Drug Policy, 16*, 191-198.

Dalgarno, P. (2007). Subjective effects of Salvia divinorum. *Journal of Psychoactive Drugs, 39*, 143-149.

Duff, C. (2005). 'Charging' and 'blowing out': Patterns and cultures of GHB use in Melbourne, Australia. *Contemporary Drug Problems, 32*, 605-655.

Duff, C., Johnston, J., Moore, D., & Goren, N. (2007). *Dropping, connecting, playing and partying: Exploring the social and cultural contexts of ecstasy and related drug use in Victoria*. Melbourne: Premier's Drug Prevention Council, Department of Human Services Victoria.

Duterte, M., Jacinto, C., Sales, P., & Murphy, S. (2009). What's in a label? Ecstasy sellers' perceptions of pill brands. *Journal of Psychoactive Drugs, 41*, 27-37.

Ess, C., & Association of Internet Researchers Ethics Committee. (2002). Ethical decision-making and Internet research: Recommendations from the AoIR ethics working committee. Available from http://www.aoir.org/reports/ethics.pdf

Eysenbach, G., & Till, J. E. (2001). Ethical issues in qualitative research on Internet communities. *British Medical Journal, 323*, 1103-1105.

Fielding, N. G., Lee, R. M., & Blank, G. (Eds.). (2008). *The handbook of online research methods*. London: Sage.

Finn, J. (1999). An exploration of helping processes in an online self-help group focusing on issues of disability. *Health and Social Work, 24*, 220-231.

Fowler, G., Kinner, S., & Krenske, L. (2007). *Containing ecstasy: Analytical tools for profiling an illegal drug market* (NDLERF Monograph Series No. 27). Adelaide: National Drug Law Enforcement Research Fund.

Fry, C. (2007a). *Making values and ethics explicit: A new code of ethics for the Australian alcohol and other drugs field*. Canberra: Alcohol and other Drugs Council of Australia. Available from http://www.adca.org.au/images/publications/ethics_code.pdf

Fry, C. (2007b). *Making values and ethics explicit: The development and application of a revised code of ethics for the Australian alcohol and other drug field* (ADCA Discussion Paper). Canberra: Alcohol and other Drugs Council of Australia. Available from http://www.adca.org.au/images/publications/ethics_discussion.pdf

Fry, C. L., Treloar, C., & Maher, L. (2005). Ethical challenges and responses in harm reduction research: Promoting applied communitarian ethics. *Drug and Alcohol Review, 24*, 449-459.

Fuchs, C. (2008). *Internet and society: Social theory in the information age*. New York: Routledge.

Gamma, A., Jerome, L., Liechti, M. E., & Sumnall, H. R. (2005). Is ecstasy perceived to be safe? A critical survey. *Drug and Alcohol Dependence, 77*, 185-193.

Gascoigne, M., Dillon, P., & Copeland, J. (2004). *Sources of ecstasy information: Use and perceived credibility* (NDARC Technical Report). Sydney: National Drug and Alcohol Research Centre.

Gibson, C., & Pagan, R. (2000). *Rave culture in Sydney, Australia - mapping youth spaces in media discourse*. Available from http://www.snarl.org/youth/chrispagan2.pdf

Greener, T., & Hollands, R. (2006). Beyond subculture and post-subculture? The case of virtual psytrance. *Journal of Youth Studies, 9*, 393-418.

Hall, G. J., Frederick, D., & Johns, M. D. (2004). "NEED HELP ASAP!!!": A feminist communitarian approach to online research ethics. In M. D. Johns, S.-l. S. Chen & G. J. Hall (Eds.), *Online social research. Methods, issues and ethics* (pp. 239-252). New York: Peter Lang.

Hall, M. J., & Tidwell, W. C. (2003). Internet recovery for substance abuse and alcoholism: An exploratory study of service users. *Journal of Substance Abuse Treatment, 24*, 161-167.

Hewson, C. (2007). Gathering data on the Internet: Qualitative approaches and possibilities for mixed methods research. In A. N. Joinson, K. McKenna, T. Postmes & U.-D. Reips (Eds.), *Oxford handbook of Internet psychology* (pp. 405-428). Oxford: Oxford University Press.

Hough, M., Warburton, H., Few, B., May, T., Man, L.-H., Witton, J., et al. (2003). *A growing market. The domestic cultivation of cannabis*. York: Joseph Rowntree Foundation.

Illingworth, N. (2001). The Internet matters: Exploring the use of the Internet as a research tool. *Sociological Research Online, 6*. Available from http://www.socresonline.org.uk/6/2/illingworth.html

Im, E. O., Chee, W., Tsai, H. M., Bender, M., & Lim, H. J. (2007). Internet communities for recruitment of cancer patients into an Internet survey: A discussion paper. *International Journal of Nursing Studies, 44*, 1261-1269.

Katz, N., Fernandez, K., Chang, A., Benoit, C., & Butler, S. F. (2008). Internet-based survey of nonmedical prescription opioid use in the United States. *Clinical Journal of Pain, 24*, 528-535.

Kazmer, M. M., & Xie, B. (2008). Qualitative interviewing in Internet studies: Playing with the media, playing with the method. *Information, Communication and Society, 11*, 257-278.

King, S. A. (1996). Researching Internet communities: Proposed ethical guidelines for the reporting of results. *The Information Society, 12*, 119-128.

Koo, M., & Skinner, H. (2005). Challenges of Internet recruitment: A case study with disappointing results. *Journal of Medical Internet Research, 7*. Available from http://www.jmir.org/2005/1/e6

Mallick, J., Johnston, J., Goren, N., & Kennedy, V. (2007). *Drugs and driving in Australia: A survey of community attitudes, experience and understanding*. Melbourne: Australian Drug Foundation.

McKee, H. A., & Porter, J. E. (2008). The ethics of digital writing research: A rhetorical approach. *College Composition and Communication, 59*, 711-749.

Measham, F., & Moore, K. (2009). Repertoires of distinction: Exploring patterns of weekend polydrug use within local leisure scenes across the English night time economy. *Criminology and Criminal Justice, 9*, 437-464.

Mendelson, C. (2007). Recruiting participants for research from online communities. *Computers, Informatics, Nursing, 25*, 317-323.

Miller, P. G., Johnston, J., McElwee, P. R., & Noble, R. (2007). A pilot study using the Internet to study patterns of party drug use: Processes, findings and limitations. *Drug and Alcohol Review, 26*, 169-174.

Miller, P. G., & Sønderlund, A. L. (2010). Using the Internet to research hidden populations of illicit drug users: A review. *Addiction*, *105*, 1557-1567.

Murguía, E., & Tackett-Gibson, M. (2007). The new drugs Internet survey: A portrait of respondents. In E. Murguía, M. Tackett-Gibson & A. Lessem (Eds.), *Real drugs in a virtual world: Drug discourse and community online* (pp. 45-58). Lanham, MD: Lexington Books.

Murguía, E., Tackett-Gibson, M., & Lessem, A. (Eds.). (2007). *Real drugs in a virtual world: Drug discourse and community online*. Lanham, MD: Lexington Books.

Murray, C. D., & Sixsmith, J. (1998). Email: A qualitative research medium for interviewing? *International Journal of Social Research Methodology: Theory and Practice, 1*, 103-121.

Myers, S., & Drill, S. (2008, 27 January). Forums for drug tips. Teens online plan binges*. The Herald Sun*.

National Health and Medical Research Council. (2002). *Statement on consumer and community participation in health and medical research*. Canberra: Commonwealth of Australia. Available from http://www.nhmrc.gov.au/publications/synopses/r22syn.htm

National Health and Medical Research Council. (2004). *A model framework for consumer and community participation in health and medical research*. Canberra: Commonwealth of Australia. Available from http://www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/r33.pdf

Petras, E. M., & Porpora, D. V. (1993). Participatory research: Three models and an analysis. *American Sociologist, 24*, 107-126.

Reid, E. (1996). Informed consent in the study of on-line communities: A reflection on the effects of computer-mediated social research. *The Information Society, 12*, 169-174.

Roberts, L., Smith, L., & Pollock, C. (2004). Conducting ethical research online: Respect for individuals, identities and the ownership of words. In E. A. Buchanan (Ed.), *Readings in virtual research ethics. Issues and controversies* (pp. 156-173). London: Information Science Publishing.

Rodgers, J., Buchanan, T., Pearson, C., Parrott, A. C., Ling, J., Heffernan, T., et al. (2006). Differential experiences of the psychobiological sequelae of ecstasy use: Quantitative and qualitative data from an Internet study. *Journal of Psychopharmacology, 20*, 437-446.

Rodgers, J., Buchanan, T., Scholey, A. B., Heffernan, T. M., Ling, J., & Parrott, A. C. (2003). Patterns of drug use and the influence of gender on self-reports of memory ability in ecstasy users: A web-based study. *Journal of Psychopharmacology, 17*, 389-396.

Rowe, J. (2004). Towards a 'thoughtful' sociology of drug use: Involving drug users in policy making. In J. Rowe & P. Mendes (Eds.), *Harm minimisation vs. zero tolerance: The politics of illicit drug policy in Australia* (pp. 113-120). Melbourne: Pearson Education.

Schneider, J. L. (2003). Hiding in plain sight: An exploration of the illegal(?) activities of a drug newsgroup. *Howard Journal, 42*, 374-389.

Seymour, W. S. (2001). In the flesh or online? Exploring qualitative research methodologies. *Qualitative Research Journal, 1*, 147-168.

Shearer, J., Johnston, J., Fry, C. L., Kaye, S., Dillon, P., Dietze, P., et al. (2007). Contemporary cocaine use patterns and associated harms in Melbourne and Sydney, Australia. *Drug and Alcohol Review, 26*, 537-543.

Singer, M. (2006). What is the "drug user community"?: Implications for public health. *Human Organization, 65,* 72-80.

Siokou, C. (2002). Seeking the vibe. *Youth Studies Australia, 21*, 11-18.

Sixsmith, J., Boneham, M., & Goldring, J. E. (2003). Accessing the community: Gaining insider perspectives from the outside. *Qualitative Health Research, 13*, 578-589.

Sixsmith, J., & Murray, C. D. (2001). Ethical issues in the documentary data analysis of Internet posts and archives. *Qualitative Health Research, 11*, 423-432.

Smith, M. A., & Leigh, B. (1997). Virtual subjects: Using the Internet as an alternative source of subjects and research environment. *Behavioral Research Methods, Instruments and Computers, 29*, 496-505.

Stetina, B. U., Jagsch, R., Schramel, C., Maman, T. L., & Kryspin-Exner, I. (2008). Exploring hidden populations: Recreational drug users. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace, 2*, article 1. Available from http://www.cyberpsychology.eu/view.php?cisloclanku=2008060201

Sumnall, H. R., Woolfall, K., Edwards, S., Cole, J. C., & Beynon, C. M. (2008). Use, function, and subjective experiences of gamma-hydroxybutyrate (GHB). *Drug and Alcohol Dependence, 92*, 286-290.

Sveningsson, M. (2004). Ethics in Internet ethnography. In E. A. Buchanan (Ed.), *Readings in virtual research ethics. Issues and controversies* (pp. 45-61). London: Information Science Publishing.

Sveningsson Elm, M. (2008). How do various notions of privacy influence decisions in qualitative Internet research? In A. N. Markham & N. K. Baym (Eds.), *Internet inquiry: Conversations about method* (pp. 69-87). Thousand Oaks: Sage.

Thornton, S. (1995). *Club cultures: Music, media and subcultural capital*. Hanover: University Press of New England.

Warburton, H., Turnbull, P. J., & Hough, M. (2005). *Occasional and controlled heroin use. Not a problem?* London: Joseph Rowntree Foundation.

Whitty, M. (2004). Peering into online bedroom windows: Considering the ethical implications of investigating Internet relationships and sexuality. In E. A. Buchanan (Ed.), *Readings in virtual research ethics. Issues and controversies* (pp. 203-218). London: Information Science Publishing.

Note: all URLs in this paper are current at 18/4/2010.