

Researching suicidal distress with LGBT communities in UK: Methodological and ethical reflections on a community-university knowledge exchange project

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The Brighton and Sussex Community-University Knowledge Exchange Programme's aim (BSCKE) was to fund projects that would lead to an 'exchange of knowledge' through collaborative work between the university and community groups, with a focus on the impact of marginalisation and issues of social exclusion. Our successful submission outlined a key concern for community psychologists involving the seeming elevated rate of suicide distress amongst lesbian, gay, bisexual, and transgendered (LGBT) individuals. The study used a participatory-action research approach and conducted an in-depth qualitative analysis of the experiences of suicidal distress and survival with mental health service users and young people who identify as LGBT. This paper reflects on the process of setting up the knowledge-exchange project before addressing methodological and ethical issues that arose during the course of the research project and the ways in which they were negotiated. It concludes by making recommendations for future applied research practice in community-university partnerships.

Understanding Mental Health Issues in LGBT Communities

In 2003 the first UK based large-scale analysis of the relationship between sexuality and mental health issues established evidence of a higher incidence of mental distress for lesbians, gay men and bisexual men and women than for heterosexuals (King et al., 2003a, 2003b). Of particular concern in this study was the prevalence of suicidal distress and serious self-harm, with 1/3 of the sample having attempted suicide on at least one occasion. This finding was consistent with research studies from other western cultures including the USA and Australia that stress concern with levels of suicidal distress amongst LGBT people (e.g., Bagley & D'Augelli, 2000; D'Augelli & Grossman, 2001; Jorm, Korten, Rodgers, Jacomb, & Christensen, 2002; McNair, Kavanagh, Agius, & Tong, 2005; McNamee 2006; Ramafedi, 1987). In a survey of 1100 LGBT respondents from Brighton and Hove (UK) conducted by *Count Me In* (2001), 40% of respondents reported serious thoughts of suicide and 20% had attempted suicide. *Diagnosis Homophobic* (Project for Advice, Counselling and Education [PACE], 1998) found suicidal thoughts and attempts linked to internalised homophobia, social

homophobia, loneliness and isolation for LGB people. Warner et al. (2004) linked higher levels of self-harm and suicidal behaviour in the LGB population to the levels of discrimination (including physical attacks and verbal abuse) they had encountered. These were significantly more than for a comparative group of heterosexual participants. Other studies show high rates of suicidal distress amongst particular LGBT groups, such as LGB youth (e.g., Herschberger & D'Augelli, 1995) and transgender youth and adults (e.g., Israel & Tarver, 1997), and higher rates of self-harm and suicide amongst lesbians than heterosexual women (e.g., McNair et al., 2005).

Together, these studies illustrate that LGBT people are more likely to experience problems with their mental health than heterosexual people and should be supported with appropriate services and legislation to protect them from discrimination. Yet, studying the mental health of LGBT people is not a straightforward issue. Despite the growing acknowledgement that some LGBT people suffer from high levels of mental distress, and that this is related to elevated levels of discriminatory practices, including physical and verbal abuse, mental health issues are often stigmatised within LGBT communities. The socio-medical construction of 'homosexuality' that led to the pathologizing of same-sex

activities and the classification of homosexuality as a mental illness (Foucault, 1978) has left a legacy that is difficult to shake off. Studies have pointed to the homophobia and heterosexism that still exists within the mental health services in the UK (e.g., PACE, 1998) and there is a well-placed resistance to psychological and psychiatric practices within LGBT communities. A qualitative account of the experiences of LGB people in the UK who had accessed mental health services noted problematic encounters that ranged from “instances of overt homophobia and discrimination, to a perceived lack of empathy around sexuality issues by the clinician” (King et al., 2003a, p. 3). Transgendered people also have their own ongoing battles as ‘gender identity disorders’ are still classified within DSM-IV (American Psychiatric Association, 1994). Thus, their identity status is embedded within discourses of mental illness and, despite political lobbying, psychiatrists still regulate gender reassignment processes (Johnson, 2007).

This poses a dilemma for those who wish to understand how LGBT people experience suicidal distress and provide appropriate services to meet their needs without reconstructing a pathologizing narrative for all. To speak of elevated rates of psychological distress or suicide related behaviour in the LGBT population runs the risk of reinforcing a relationship between sexuality/trans identity status and mental health issues that might imply that mental health problems are simply associated with being LGBT. This is not the case. Rather, recent research in the area suggests that suicidal distress is associated with a range of psychosocial ‘stresses’, including victimisation, lack of support, family problems, knowing someone who has made suicide attempts, homelessness, substance misuse and other psychiatric problems (Ramefedi, 1999), rather than a specific identity itself. As Meyer (2003, p. 674) proposes stigma, prejudice and discrimination create such a hostile environment that it leads to mental health problems that are the result of ‘minority stress’. Despite the growing evidence that suicidal distress is linked to discrimination few studies have addressed the individual narratives of LGBT people who experience this distress. Equally, the methodological design of large-scale quantitative studies affords little ongoing support

for participants after questionnaires have been submitted. This paper reflects on the process of using participatory-action research within the context of a community-knowledge exchange programme as an alternative methodological approach for understanding LGBT suicidal distress.

Setting Up the Research Project: The Brighton and Sussex Community Knowledge Exchange Program

The initial idea for this project arose at a ‘matching meeting’ hosted by the Brighton and Sussex Community Knowledge Exchange Programme (BSCKE) in April 2005. BSCKE is part of the wider Community University Partnership Programme (CUPP) and is funded by Higher Education Funding Council for England (HEFCE) under the Higher Education Innovation Funding Scheme (see HEFCE, 2006, for further details). Community-university partnerships are a pioneering development in higher education policy to “reconstruct the relationship between universities and society through action research” (Greenwood & Levin, 2000, p. 85). Such programmes have become popular since the late 1990s to foster allegiances between local universities, businesses and community organisations. BSCKE is one such programme and defines itself as “a groundbreaking initiative to support and fund mutually beneficial partnerships between communities and universities in Brighton and Hove and coastal Sussex” tackling “real community problems, recognizing and addressing diversity and engaging with socially excluded groups”. Key to this is the principle of ‘knowledge exchange’ where

BSCKE [also] aims to facilitate the exchange and growth of knowledge across sectors. University partners provide practical support to community, voluntary, public sector and social enterprise organisations and networks, grounded in academic understanding and expertise. In their turn, community partners contribute to lasting culture change within the universities by bringing real issues into teaching and research (BSCKE, 2006).

In the 2004-2006 funding round BSCKE offered funding of up to £20,000 for approximately 20 small-scale projects. At the 'match-meeting' the author met with the co-ordinator of MindOut, a mental health support group for LGBT people in the Brighton and Hove region. It was immediately clear that we had similar interests and concerns for addressing mental health issues in the LGBT community. My previous research addressed issues of LGBT mental health (e.g. Johnson 2007; King et al., 2003a; Warner et al., 2004) and MindOut had just received funding from the South East Development Centre of the *National Institute for Mental Health England* (NIMHE) to conduct a pilot project on suicide prevention in the local LGBT community. This money was being used to employ a development worker to work with agencies and services, including A&E, mental health services and community groups to ascertain levels of prevalence of self-harm and suicide related behaviour in the LGBT community in Brighton and Hove. Their second task was to pilot outreach methods and evaluate effective strategies for suicide prevention, including a model of peer support. While MindOut were delighted to have received funding for a development worker they realised the outreach strategies would be improved if they were underpinned by a greater understanding of the needs of those who attempt suicide and/or self-harm. They had been told by NIMHE that there was no possibility of funding for a researcher that would make up a Research and Development post and they were looking to BSCKE for support with their community intervention. Thus, together we had a 'match' in interest and drew up a proposal that sought to meet a range of outcomes under the criteria set out by BSCKE. These included:

- 1 A greater understanding of the meanings and experience of self-harm and suicidal distress in the LGBT community in Brighton and Hove.
- 2 A positive effect on social inclusion for those who are at risk of suicide/self-harm related behaviour and in distress.
- 3 Knowledge to inform national and international understanding of the

narratives of LGBT individuals as they describe and interpret factors that impacting on their mental health (distributed through local community forums as well as academic papers and teaching strategies).

- 4 Knowledge that will inform suicide prevention strategies locally and nationally, including critiques of any discriminatory practices, and aid in the reduction of suicide (distributed through local community forums as well as academic papers and teaching strategies).
- 5 A sustainable relationship between the university and community organisations in relation to understanding and addressing the needs of local LGBT people.

In an effort to capture the extent of suicidal distress within the local community we initially designed a project that sought to recruit people through as wide a network as possible. We intended to include those who were attached to a community organisation and those who were not through posting open-ended questionnaires on on-line forums and wider advertisements in the local LGBT press. Within this we hoped to interview a sample that included older gay men, young LGBT people, transmen and transwomen and LGBT people from BME groups. However, in the feedback from Round 1 of the funding bid we were asked to reduce the scale of the project to a budget of £11,000. This was extremely disappointing and placed limitations on what we were able to do. We met to consider whether it was feasible or worthwhile conducting a much smaller project. At the same time I was contacted by the CUPP helpdesk who had received another enquiry for research into suicide related behaviour from another local group. *Allsorts* provides support to gay, lesbian, bisexual, transgendered and unsure (LGBTU) youths, and they had recently lost 2 group members to suicide. After a lengthy process of discussion with the manager of Allsorts they agreed to become a stakeholder in our project and enabled us to formulate a more contained research proposal that met the objectives of promoting social inclusion and gaining a thorough knowledge of issues faced by hard to reach

groups.

A participatory-action research approach to understanding LGBT suicidal distress

With a relationship between sexual identity and suicide risk already established through large-scale quantitative findings (e.g. King et al., 2003a; Ramefedi et al., 1998) we focused on designing a research approach to gain a more detailed understanding of the specificities of suicidal distress in some LGBT peoples' lives. Specifically, we were looking to compare and contrast meanings and experiences of suicide related behaviour and survival in two LGBT groups considered 'at-risk' of suicide: those with mental health issues and young people. Only a few studies have conducted qualitative interviews with people who have suicidal thoughts or have made suicide attempts (e.g., Asberg, Samuelsson, Wiklander, 2003; Greenland, Prior, Scourfield, & Smalley, 2004; Kidd & Krul, 2002) with fewer still focusing on LGBT issues (e.g. Fenaughty & Harré, 2003) and none that we are currently aware of have focused on young LGBT people and/or LGBT mental health service users.

Working in this relatively recent area within the context of the BSCKE programme we operated within the principles of community psychology (e.g., Harper & Schneider, 2003; Nelson, Lord & Ochocka, 2001; Nelson & Pilleltsky, 2005; Rappaport, 1987; Rappaport & Seidman, 2000) and participatory-action research (e.g., Brydon-Miller, 2004; Dockery, 2000; Greenwood & Levin, 2000; Park, 2001) by seeking to involve participants and community group representatives within the research process in order to create a sense of belief in, and ownership of, the projects' objectives and outcomes, as well as ensuring appropriate post-research support for participants from the LGBT community groups.

Nine participants (five at MindOut and four at Allsorts) took part in focus groups to design the interview questions and approve the final schedule. They had all met with the researcher on at least one occasion prior to the focus group, if not more, as the researcher spent time in both community groups discussing the aims and objectives of the research project and responding to questions during drop-in sessions. At the same time participants were informed that the university researchers also identified as lesbian or gay in order to emphasise that this was a

participatory-action research project, acknowledge our own commitment to the local LGBT community, and reassure participants that they were not 'objects' of research. The focus group discussions generated themes that participants thought were relevant to LGBT people who experienced suicidal distress. The interview schedule was developed in order to capture this range of themes and experiences and, prior to approving the schedule, participants were asked to reflect on whether it was appropriate for describing their own experience. Twelve people took part in one-to-one interviews (seven from MindOut and five from Allsorts) and participants had the option of being interviewed by either a male or female researcher. Considerable care was taken to layer in levels of support for our participants so that they had the opportunity to discuss their participation with a community worker both before and after the interview. All participants were provided with a list of local and national services and help-lines, but the community groups played a crucial role in ensuring participants had sufficient support for their emotional needs and were available to provide continuing support in the weeks following the interviews. A number of community dissemination events were organised where participants from both groups reflected on the process of being involved in the project and contributed to further community initiatives to tackle suicidal distress. While this summary of our approach adheres to ethical guidelines and the principles of participatory-action research, a number of methodological and ethical issues arose during the research process. These are discussed in the following sections.

The Research Process: Methodological Principles and the Practice of Negotiation

In line with the principles and goals of community psychology and the BSCKE program this project aimed for a collaborative framework throughout. The initial research aims and objectives were constructed via a process of negotiation between the author and the community supervisor from MindOut. Shortly afterwards the research team was joined by a research assistant and a community representative from Allsorts and further development took place. Collaboration and service-user involvement and evaluation was

emphasized at every juncture and each stage raised issues that required reflection and negotiation in order to maintain a balanced, working relationship. It was the first occasion that I had worked in such a partnership and the first time the community groups had co-run a research project. Needless to say much was learnt on both sides of the partnership and two examples are discussed here:

Service-user engagement: A key principle of participatory-research is the engagement of service-users in steering group committees and other decision-making teams in order to learn from their valuable perspectives and insights. The first task for our partnership was to employ a research assistant who would conduct many of the interviews. Thus, the interview panel for the research assistant post consisted of the community supervisor from MindOut, the academic supervisor (the author), an external academic from within the university, and a service-user from MindOut. In our discussion it became clear that there were differences in our preferences for candidates and, as this was the first collaborative task, the negotiation could have been awkward and detrimental to the goal of promoting service-user perspectives. The community partner and I had agreed on the importance of service-user involvement, but I appeared less able to take on the service-user's perspective. Their preferred candidate had less empirical research experience than other candidates and the academic member of staff and I were more confident in the abilities of other candidates, yet I was disappointed that I seemed to be 'pulling rank' at the first point of difference. With clear employment guidelines for distinguishing candidates against set job criteria it was possible to negotiate this difference in opinion in a productive manner, however it made it clear from the very beginning of the project that collaborative working required decision making based on existing knowledge and expertise, rather than through a process of mutual agreement.

Design of interview research questions: After co-facilitating focus group discussions with community group members on 'what do we want to know about LGBT people who experience suicidal distress', the university partners asked the community partners to draft some research

questions that they thought should be part of the interview schedule. The resulting questions showed clear distinctions between the community groups existing knowledge of the experience of suicidal distress and the academic mores of qualitative methodology design. For example, one community group posed questions such as 'how has the homophobia you have experienced influenced your suicidal thoughts and feelings?' while the university team generated questions such as 'can you tell me about a time when you felt suicidal?' These differences led to a fairly tense and lengthy discussion where the community groups felt the questions needed to be more specific about experiences of homophobia and the university partners stressed the need for questions to be open-ended and 'not leading', if they were to have academic credibility. Again, as with the previous task, the university partners' knowledge of research design won out over the community groups' knowledge of experiences of suicidal distress their service-users reported. However, the power imbalance in the partnership started to have some negative effects. At this stage the university partners were carrying out most of the tasks, as these relied on research expertise, and the community groups held clear expectations about what they thought the project would find. There was frustration on both sides, but for the university partners it felt like the research had been commissioned by the community groups, rather than as a project that would emerge from a collaborative and equal partnership. This dynamic could have been detrimental to the progress of the research but the relationship shifted suddenly after the project stalled when seeking ethical clearance from the CUPP research ethics board.

Ethical Procedure: Considering Principles and Negotiating Tensions

In line with established ethical guidelines (e.g., British Psychological Society, 2000) we gave due consideration to key principles such as 'informed consent', 'debriefing', 'confidentiality and anonymity' and 'protection of participants and researchers', and attempted to embed good practice around these principles within the methodological design. We were particularly aware that the research raised a number of ethical dilemmas given its focus on suicidal distress and

the incorporation of two groups defined as ‘vulnerable’: people with mental health problems and ‘young people’. The participatory design and co-ownership nature of the research also raised specific issues, in relation to ‘confidentiality and anonymity’, while aiding others, such as ‘debriefing’ and ‘protection of participants and researchers’.

‘Confidentiality and Anonymity’: As participants had been engaged in the methodological design of the interview questions, were debriefed by both the researcher and their community worker and had ongoing support from their community group, the main ethical concern for the research team was ‘confidentiality and anonymity’. It was clear that complete confidentiality could not be guaranteed to the participants because of the topic area. Thus, participants were informed that their accounts would be treated as confidential unless they mentioned any current plans to take their life. It was agreed with participants before the interviews that this type of information would be discussed with their community group worker immediately after the interview so that appropriate interventions and support could be provided. Anonymity was also a major consideration because the research was co-owned by the university and ‘named’ community groups, and this factor jeopardised the standard aim of protecting the anonymity of the participants. All participants were informed that it would not be possible to guarantee their anonymity as the names ‘MindOut’ and ‘Allsorts’ would appear on the report and interview extracts would be used to illustrate the findings. Thus, there was an increased chance of participants being recognised. All respondents were aware of this and given the opportunity to withdraw from the research.

‘Debriefing’ and ‘protection of participants and researchers’: The participatory nature of the research design reassured us that individual participants would be sufficiently supported through both pre- and post-interview briefings with their community worker. Furthermore, due attention was paid to the possible impact of the research material on members of the research team, such that regular debriefing meetings were organised for the research assistant with the community supervisor and the independent

transcriber of the interviews was offered similar debriefing sessions if they found the material distressing.

Despite these actions and preparations we were informed that the ethics panel had strong reservations about whether the research should proceed because of their perception of the participants’ ‘vulnerability’ and ‘risk’ in relation to clinical mental health provision. Others have addressed the limitations of Research Ethics Boards for reviewing participatory-action research (e.g., Khanlou & Peter, 2005) yet given our panel was constructed specifically to consider CUPP projects we were surprised by the implications of some of their recommendations. We were, perhaps rightly, instructed to make our information sheets more user-friendly, which in due course we did. This was regardless of the ‘participation’ of participants in the research design from the beginning and our sense that information sheets in a traditional sense lacked meaning: participants knew why they were taking part in the research, had helped design the interview schedule and approved it. We were more concerned about the ethics panel’s apprehension at the lack of a clinically trained mental health professional (e.g., clinical psychologist or psychiatrist) in the research team, and the suggestion that it was too ‘risky’ to speak of suicide as participants might become ‘traumatised’ and the researcher would not be able to manage the situation. It seemed that none of the references to the pre-briefing or debriefing meeting with their community group worker reassured them that, as a partnership, we were experienced enough to conduct the research without causing harm to the participants.

Understandably the community groups felt completely undermined in terms of their expertise in supporting vulnerable LGBT people – particularly MindOut who were already developing intervention strategies for the suicidal LGBT people attending their group, and who were also our participants. Moreover, the request for clinical mental health provision was equally problematic given the poor experience that many LGBT have had within statutory services (as was pointed out in the proposal). It took several months, a raft of emails and an eventual complaint about the undermining connotations of their (lack of) assessment of community group

expertise before we were eventually given permission to proceed.

At the time, one benefit of a mutual adversary was the strengthening of the relationship between the community partners and the academic partners. Yet, in the context of the research project this meant renegotiating my role so that I no longer felt the ‘university partner’, but rather the person who worked at the university who also struggled with wider university structures. Retrospectively, the experience was also positive in terms of the types of outcomes BSCKE was interested in. A great deal of ‘knowledge-exchange’ took place as we discussed our understandings of ethical concepts and institutional structures within our own organisations as we reflected on and negotiated the ethical process. Of particular interest was the different responses the two groups had when ascertaining what the ethics panel regarded as ‘risky’ or ‘vulnerable’, principles they related to ‘informed consent’, but in different ways.

Refining Ethical Concepts in Collaborative Research

‘Vulnerability’, ‘Risk’ and ‘Informed Consent’: These concepts raised different concerns across the two groups. For instance, Allsorts staff attended to the vulnerability status of their participants prior to the interviews and held lengthy discussions about whether taking part in the research was the ‘right option’ for them. This form of ‘risk assessment’ was underpinned by an acknowledgement that suicide and mental health issues were not widely discussed within the youth group, most of the young people had not previously taken part in research, and the group had recently lost two members to suicide. Thus, Allsorts wanted to be sure that their participants knew that they were consenting to take part in research and understood the boundaries of a research interview. They were also performing a risk assessment in terms of considering whether some members might find counselling a more appropriate option than taking part in the research, or if they might also require additional emotional support after the research interview. In contrast, MindOut workers were less concerned with ‘risk assessments’ as they were constantly involved in assessing their members suicidal risk status. For them, all their participants were

‘vulnerable’ as they lived with fluctuating intensities of suicidal ideation and intension. As such, informed consent was the crucial element to ensure so that we were confident that participants were aware of what the research involved and what the ‘risks’ in terms of taking part might be to them – in particular that they might be recognised in published material. We all agreed the community workers were best placed to make these assessments with participants rather than an external, clinical health professional because of their longstanding relationships with the participants and their knowledge of them.

Confidentiality and Anonymity:

Confidentiality was a key ethical concern given that it was possible participants might discuss immediate plans to take their life. This did happen in one of the interviews and the interviewer re-informed the participant that they would have to discuss the matter with their community worker after the session. This admission had far more impact on the researcher than either the participant or community supervisor who both had more experience in discussing these types of emotions. Again, it points to the importance of collaborative research projects for topics such suicidal distress, as the community group were able to provide an immediate debriefing for the researcher and subsequent support for both participant and researcher, if necessary. Anonymity was an early concern as we recognised that one downside of community-university partnership projects is the increased likelihood of participants being recognised because of their association with particular community groups. At the same time having the community group’s name on the final report can be extremely useful in accessing further funds to support their initiatives and interventions. We were clear with participants that we could not assure their anonymity and some people decided not to take part in the interviews because of that. However, this issue came up again in the latter stages of the project once the findings and analysis section had been drafted. I was asked by a community group worker if I could remove identifying annotations from the end of interview extracts that stated which group the participant attended, their gender and age. My immediate concern was that

to remove this information would make the data meaningless: for example, how is it possible to make a claim about a transwoman's experience, or differences between young LGBT people and LGBT mental health services users if we cannot identify data with those categories? Yet, I also appreciated the position of the community partner who was concerned that these annotations contravened confidentiality as well as anonymity because they were able to identify their individual group members from the annotations alone. In light of this, we agreed to remove all age references in the hope that it will provide a little more shelter for the identities of the participants. However, we remain aware that co-owned university-community partnership projects require careful ongoing consideration in terms of the ethical dilemmas they raise.

Critical Reflections and Future Recommendations

The findings for this study were launched to a local audience on 24 January 2007 in Brighton and Hove, with a set of recommendations for understanding suicidal distress and promoting survival in LGBT communities. In this context the project has been a great success providing rich data and insight into the isolation and discrimination that some LGBT people encounter (see Johnson, Jones, Faulkner, MindOut, & Allsorts Youth Project, 2007). The project has resulted in a 'knowledge-exchange' that is mutually beneficial for both the LGBT community and the university. I have already incorporated the research design, methodological and ethical considerations into a master's module on qualitative research and use the project in its entirety as an example of Community Psychology in Practice in the undergraduate psychology programme. The community groups have a substantial set of findings to use in their own practice, distribute through community forums and use to inform LGBT suicide prevention strategies. Particular successes are that MindOut received 5 years further funding in April 2007 and Allsorts have been able to draw on the research in planning interventions to tackle homophobic bullying in schools. We also have a strong working relationship and a willingness to maintain the collaboration. Yet, we are also able to make a number of recommendations for future applied

research practice in the context of community-university knowledge exchange programmes.

The participant experience - The feedback from participants about the benefits of the research approach has been most positive. Given our finding that suicidal distress is an outcome of acute isolation and that survival can be promoted through 'connections' (Johnson et al., 2007) it was encouraging to hear anecdotal accounts from MindOut participants about the benefits of taking part in the research. This included feeling more connected to both their community group and the wider LGBT community. At MindOut the research was positioned as part of a wider project of tackling suicide in the LGBT community alongside other initiatives such as organising a special edition of the local gay magazine *GScene* to focus on the stigma of mental illness, and holding the first closed *ASIST* suicide intervention training weekend for LGBT people in the UK. I attended this weekend and it was one of the few occasions where I felt taken out of the 'university' role and submerged in the community experience. Here, our working groups consisted of a mixture of LGBT professionals from a multitude of backgrounds and LGBT service-users with a range of experiences of supporting people with mental health issues. The challenges each of us faced in meeting the training tasks resulted in an atmosphere of collaboration and community investment, as well as increased confidence to discuss suicidal distress and intentions with those who might be in need. Participants at Allsorts also spoke positively about taking part in the research in terms of seeing 'how far they had come' as well as expressing a desire to mentor younger LGBT people who might be experiencing similar circumstances they had moved on from. These accounts demonstrate to us the value in participatory-action research approaches in creating some degree of personal and social transformation. The collaborative relationship with community partners is key to understanding the impact of research on participants' lives, primarily through their informal feedback and monitoring of participants ongoing emotional wellbeing. The challenge for the future is to maintain this sense of empowerment and connection for our participants via new initiatives to challenge

stigma about suicide and sexuality in both the LGBT and wider community.

Future Collaborative Practice –

Collaboration was central to the success of the project and took place through regular steering group meetings. These were arranged by the BSCKE co-ordinator. Her role proved crucial in problem solving and advising on more difficult aspects of the project (e.g., ethical approval) as well as in negotiating differences between the community-university partners. However, the time required for collaborative research was drastically under-estimated in the original research proposal. With the additional lengthy delay in ethical approval the project was soon behind schedule culminating in the end of the research assistant's contract before the analysis was finished. The project was eventually completed by the academic partner six months later than expected. Future projects need to be aware of the time required for building relationships and negotiating points of disagreement, and need to incorporate this into any funding bid as missing deadlines could have serious implications if community groups are reliant on the research for funding bids.

Funding Issues – Knowledge-exchange projects utilise a model that has been successful in university-business collaborations and applies it to community settings. The ideological values that underpin 'knowledge-exchange' should be applauded but in our reality it took two already under-funded organisations (e.g. modern universities and cash-strapped community organisations serving disadvantaged groups) and provided a skeletal budget to effect social change. As such, the research produced is excellent value for money, but in a time when UK Research Councils are beginning to fund universities at full economic cost it must be noted that much of the work in community-university partnerships is generated by the good will of individual university departments, groups and actors. Funding is equally crucial for sustaining relationships between community organisations and the local university. Initiatives such as BSCKE can begin the process of forging connections but subsequent funding is required if the partnerships are to create ongoing socially relevant research agendas that serve local marginalised groups, and redesign the teaching

and learning environment within the academy.

The ethics of knowledge-exchange – Clear guidelines are required for the process of evaluating ethical dilemmas in community-knowledge exchange programmes. Research Ethics Boards need representatives adept in the principles, goals and procedures of participant-action research and who will recognise and value community group expertise. Ethics panels should endeavour to include community group representatives who can comment and advise on their areas of expertise. It should not be assumed by ethics boards that talking about sensitive areas such as 'suicide' or 'sexuality' will traumatise participants: With sufficient layers of support participating in research can have an empowering effect and lead to personal change. When conducting sensitive research projects planners need to fully consider support for everybody that partakes, including researchers, freelance transcription providers, as well as participants and community co-ordinators. Finally, the impact of co-ownership of research raises issues of confidentiality and anonymity within qualitative studies of close-knit community groups, as it is possible that participants' accounts will be recognised. The impact of this requires evaluating prior to the research process.

Redefining Community-university Partnerships – Community-university partnership programmes are a ripe source of funding for community psychologists. They foster similar goals and objectives and demand the use of participatory-action research methods that involve participants throughout the research process in order to facilitate social action and change at community level. In many respects we have been successful in doing this, but overall the responsibility of the research has remained firmly within the university. This has been for a number of reasons that relate to the administrative aspects of community-university partnerships. While it is possible to take the university to the community by arranging meetings in community spaces rather than at the university, or make a visible presence at community events, the overall procedural control for community-university partnerships remains firmly within existing university structures. BSCKE itself is housed on the university campus and funded through HEFCE. The initial proposal had to be

accompanied by a budget with staffing costs approved through the personnel department in the university. The Research Ethics Board was located in the university and had no community group representatives. These existing university structures need to be scrutinised and reformulated in light of new learning from knowledge-exchange programmes. Thus, transformation within university administrative structures and pedagogical approaches is also crucial if knowledge-exchange programmes are to be successful in leading an applied research agenda that serves the needs of marginalised sectors of society.

References

- American Psychiatric Association. (1994). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.). Washington, DC: Author.
- Asberg, M., Samuelsson, M., & Wiklander, M. (2003). Shame reactions after suicide attempt. *Scandinavian Journal of Caring Sciences*, 17, 293-300.
- Bagley, C. & D'Augelli, A. R. (2000). Suicidal behaviour in gay, lesbian and bisexual youth. *British Medical Journal*, 320, 1617-1618.
- British Psychological Society, (2000). *Code of conduct, ethical guidelines and principles*. Leicester: Author.
- Brydon-Miller, M. (2004). Using participatory action research to address community health issues. In M. Murray, (Ed.), *Critical health psychology* (pp. 187-202). Basingstoke: Palgrave.
- Brighton and Sussex Community-University Knowledge Exchange Programme. (2006). Brighton and Sussex Community Knowledge Exchange Program – Project Guidance. Available at <http://www.brighton.ac.uk/cupp/projects/exchange.htm#guidance> [Accessed 30/12/2006]
- Count-me-in (2001). *Findings from the lesbian, gay, bisexual, transgender community needs assessment 2000*. Brighton & Hove.
- D'Augelli, A. & Grossman, A. H. (2001). Disclosure of sexual orientation, victimisation, and mental health among lesbian, gay, and bisexual older adults. *Journal of Interpersonal Violence*, 16, 1094-1098.
- Dockery, G. (2000). Participatory research: Whose roles, whose responsibilities. In C. Trumen, D. M. Mertens, & B. Humphries, (Eds.), *Research and Inequality* (pp. 95-110). London: UCL Press.
- Fenaughty, J. & Harré, N. (2003). Life on the seesaw: A qualitative study of suicide resiliency factors for young gay men. *Journal of Homosexuality*, 45, 1-22.
- Foucault, M. (1978). *The history of sexuality: Volume 1. An Introduction*, trans. Robert Hurley. London: Random House.
- Greenland, K., Prior, L., Scourfield, J., & Smalley, N. (2004). Services for suicidal young people: Qualitative research on lay and professional perspectives. *Youth and Policy*, 83, 1-18.
- Greenwood, D. J., & Levin, M. (2000). Reconstructing the relationships between universities and society through action research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.) (pp. 85-106). Thousand Oaks, CA: Sage.
- Harper, G. W. & Schneider, M. (2003). Oppression and discrimination among lesbian, gay, bisexual, and transgendered people and communities: A challenge for community psychology. *American Journal of Community Psychology*, 31, 243-52.
- Higher Education Funding Council for England. (2006). Higher Education Innovation Fund. Available at <http://www.hefce.ac.uk/reachout/heif/heif1.asp> [Accessed 30/12/2006]
- Herschberger, S. L., & D'Augelli, A. R. (1995). The impact of victimization on the mental health and suicidality of lesbian, gay and bisexual youths. *Developmental Psychology*, 31, 65-74.
- Israel, G. E., & Tarver, D. E. II (Eds.) (1997). *Transgender care: Recommended guidelines, practical information and personal accounts*. Philadelphia: Temple University Press.
- Johnson, K. (2007) Transsexualism: Diagnostic dilemmas, transgender politics and the future of transgender care. In V. Clarke & E. Peel (Eds.) *Out in psychology: Lesbian, gay, bisexual and trans perspectives* (pp.

- 445-464). London: Wiley Press.
- Johnson, K., Jones, H., Faulkner, P., MindOut and Allsorts Youth Project (2007). *Understanding suicidal distress and promoting survival in LGBT communities*. Brighton & Hove: HSPRC [available from www.spectrum-lgbt.org] [Accessed 29/04/06]
- Jorm, A. F., Korten, A. E., Rodgers, B., Jacomb, P.A., & Christensen, H. (2002). Sexual orientation and mental health: Results from a community survey of young and middle-aged adults. *British Journal of Psychiatry*, 180, 423-427.
- Khanlou, N., & Peter, E. (2005). Participatory action research: Considerations for ethical review. *Social Science & Medicine*, 60, 2333-2340.
- Kidd, S. A., & Kral, M. J. (2002). Suicide and prostitution among street youth: A qualitative analysis. *Adolescence*, 37, 411-30.
- King, M., McKeown, E., Warner, J., Ramsay, A., Johnson, K., Cort, C., Davidson, O., & Wright, L. (2003a). *Mental health and social wellbeing of gay men, lesbians and bisexuals in England and Wales*. London: Mind Report.
- King, M., McKeown, E., Warner, J., Ramsay, A., Johnson, K., Cort, C., Wright, L., Blizard, R. and Davidson, O. (2003b). Mental health and quality of life of gay men and lesbians in England and Wales: Controlled, cross-sectional study. *British Journal of Psychiatry*, 183, 552-558.
- Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin*, 129, 674-697.
- McNair, R., Kavanagh, A., Agius, P. & Tong, B. (2005). The mental health status of young adult and mid-life non-heterosexual Australian women, *Australian and New Zealand Journal of Public Health*, 29, 265-267.
- McNamee, H. (2006). *Out on your own: An examination of the mental health of young same-sex attracted men*. The Rainbow Project, Belfast. Available at <http://www.rainbow-project.org/documents/OutonYourOwn.pdf> [Accessed 20/11/06]
- Nelson, G., Lord, J., & Ochocka, J. (2001). Empowerment and mental health in community: Narratives of psychiatric consumer/survivors. *Journal of Community and Applied Social Psychology*, 11, 125-142
- Nelson, G., & Prilleltensky, I. (Eds.) (2005). *Community psychology: In pursuit of liberation and well-being*. Basingstoke: Palgrave Macmillan.
- Park, P. (2001). Knowledge and participatory research. In P. Reason & H. Bradbury, (Eds.) *Handbook of action research: Participative inquiry and practice* (pp. 81-90). London: Sage.
- Project for Advice, Counselling and Education. (1998). *Diagnostic homophobic: The experiences of lesbians, gay men and bisexuals in mental health services*. London: Author.
- Ramefedi, G. (1987). Adolescent homosexuality: Psychosocial and medical implications. *Pediatrics*, 79, 331-337.
- Ramefedi, G. (1999). Sexual orientation and youth suicide. *Journal of the American Medical Association*, 282, 1291-1292.
- Ramefedi, G., French, S., Story, M., Resnick, M. D., & Blum, R. (1998). The relationship between suicide risk and sexual orientation: Results from a population-based study. *American Journal of Public Health*, 88, 57-59.
- Rappaport, J. (1987). Terms of empowerment/exemplars of prevention. *American Journal of Community Psychology*, 15, 121-148.
- Rappaport, J., & Seidman, E. (2000). *Handbook of community psychology*. New York: Kluwer Academic/Plenum Publishers.
- Warner, J., McKeown, E., Griffin, M., Johnson, K., Ramsay, A., Cort, C. and King, M., (2004). Rates and predictors of mental illness in gay men, lesbians and bisexual men and women: Results from a survey based in England and Wales. *British Journal of Psychiatry*, 185, 479-485

Acknowledgements and Disclaimers

The project was funded and supported by Brighton and Sussex Community Knowledge

Exchange programme for which we are grateful. Thank you to the participants and community group workers from MindOut and Allsorts, Helen Jones, Emma Walsh, Paul Faulkner and Dana Cohen for their contribution to the research process, discussion, collaboration and negotiation, without which the paper would not exist. It should be noted however that this paper is published with the permission of my community partners as a single authored article, rather than co-authored as the spirit of community-knowledge exchange might expect. This is to recognize that despite many insights emerging from our shared discussion the reflections on methodology and ethics presented here are inevitably my own and not the responsibility of other team members.

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