Re-Envisioning Member Checking and Communicating Results as Accountability Practice in Qualitative Research:
A South African Community-Based Organization Example

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Abstract: Ethical considerations in communicating results to participants in community-based qualitative research are scrutinized less than in medical or genetics research. We report on ethical issues considered in planning, preparing and returning of study findings to members of a community-based organization who provide care and support services in their community in rural area in KwaZulu-Natal, South Africa. Using returning results as fulcrum, we explore the ethics of member checking and dissemination of findings. We propose revising these activities through ritual criticism aiming for the re-examination of routine ethics systems for the evaluation and improvement of practice. A case example illustrates how returning results comprise accountability practices through methods that are relevant, accessible, meaningful and useful to study participants. Finally, we consider how the dissemination of results to a wider audience might also be performed as accountability practices with deference to participants. Attention to representing results in forms that resonate with participants’ frames of reference is called for. The term accountability practices or taking-it-back practices might describe the acts more authentically than current conventions motivating researchers to review current philosophical, ethical and methodological positions on member checking, returning results and dissemination practices.

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1. Introduction

Reciprocity between researchers and participants is an essential component of community-based qualitative research (CBQR) (SOFAER, 2014). Significant attention is paid to what community-based researchers can learn from CBQR and comparatively less attention is invested in how researchers can give back to the communities that they research (FERNANDEZ, KODISH & WEIJER, 2003). There is an ethical imperative in community-based research for authentic reciprocity regarding information, data, knowledge or evidence obtained from communities, which is often not faithfully implemented (BRADLEY, WERTH & HASTINGS, 2012; FERNANDEZ et al., 2003). This imperative compels researchers, at the outset, to intentionally include member checking, returning results and dissemination phases as a part of the research cycle instead of viewing them as optional addendums. Given that community-based research may span a range from "transactional (one way university to community) engagement" to "transitional (beyond one-way including consultation and collaboration)" to "transformational (full reciprocal) community engagement" this ethical imperative holds researchers accountable to engage reflexively about emergent data regardless of the level of community engagement in other aspects of the research (BOWEN, NEWENHAM-KAHINDI & HERREMANS, 2010, p.298). [1]

The current debate in medical research, specifically genetics research, relates to also returning results to research subjects (BURKE, EVANS & JARVIK, 2014). The concern revolves around whether revealing to participants that they may be at risk to develop a medical condition is beneficial or harmful (LONG, STEWART & MCELST, 2017; LONG, STEWART, CUNNINGHAM, WARMACK & MCELST, 2016). Should a medical doctor's discovery, while doing genetics research, that a participant is at genetic risk for developing a medical condition be shared with participants? Revealing such information may have implications for life and death decisions as well as serious long-term and short-term health impacts for individuals, groups and communities. However, issues such as reliability of the results and probability that the potential disease will manifest are at play. Researchers must weigh the risk of the participant's right to be informed about their health status against the probability that the participant will develop the disease before, causing undue distress by informing the participant of their potential risk. Less life-threatening but no less impactful are results from research projects about social and community issues. What are the ethical motivations for how results should be checked and communicated to participants and beyond? Autonomy and respect for persons may be the foundational ethical principles for researchers to consider in both these instances (CLOW, 2005; DHAI, 2008; MILLER & BOULTON, 2007). Autonomous choice is at the core of informed consent and is intended as a form of independent acquiescence to participate in research. This understanding of autonomy has long been prominent in bioethics: It stresses the value of participants being adequately informed, the importance of participants' capacity to process this information, and the absence of coercion or manipulation on the part of researcher (CHAMBERS, 2014; DHAI, 2008; MILLER & BOULTON, 2007). Despite the fact that these preconditions seem evident, actively engaging with participants regarding the access and handling of data is
attended to in practice more at the start of the research process than it is at the end where the fate of research results is determined (BIRT, SCOTT, CAVERS, CAMPBELL & WALTER, 2016). [2]

Researchers have noted that engaging communication about data during and after data collection is an issue that is seldom explicitly addressed in research settings (FERNANDEZ et al., 2003; HOLLOWAY & TODRES, 2007). There is less specification on how to confirm the results of research with participants (member checking) and if / when research results should be conveyed back to communities (McDAVITT et al., 2016; McSHANE, DAVEY, ROUSE, USHER & SULLIVAN, 2015). Scant attention is given to what forms these practices should take and what at what stage of the research process should it should take place (BIRT et al., 2016). We assert that communication about data during and after the research process is an ethical imperative and ensconced within the principles of autonomy and respect for persons. This assertion is based on the idea that what researchers call "data" participants perceive as personal information about their lives. Social accountability should be held as a lens through which researchers filter the processes of communication about data to participants (individuals and communities). This process includes member checks, returning results, and disseminating data to relevant audiences. These procedures may be implemented justifiably to serve the needs of communities rather than as mere obligation or debt on the part of researchers to the communities that they work with. [3]

Procedural ethics refers to the ritual processes outlined and governed by academic conventions. In a process dominated by procedural ethics the researcher seeks and usually receives ethical approval for research studies via institutional review boards. Alternatively there is "ethics in practice" which pertain to the day-to-day ethical issues that arise in practice (GUILLEMIN & GILLAM, 2004, p.261). An ongoing debate has been initiated in this journal inviting discussion on the multilayered socially constructed nature of ethical decision-making in qualitative research (ROTH, 2005). Ethics in practice encourages a position of reflexivity whereby researchers constantly take stock of their actions and their role in the research process and subject these to the same critical scrutiny as the rest of their data (GUILLEMIN & GILLAM, 2004; NAIDU, 2014; NAIDU & SLIEP, 2011). CHAMBERS (2014, p.367) observes that ritual has become a "bad word" signifying conformity, echoing the JUNGian notion that symbols devoid of intention become idols and thereby cease to serve a social purpose. Reflexivity in research settings encourages that attention be given to ritual to align with a social purpose. Here steps are taken to recognize the power of ritual to constitute distinctive social relations and to judge whether such relations are morally just (CHAMBERS, 2014). The example of informed consent in a clinical setting provides reference for how an activity can become a ritual if it is not aligned with its intended social purpose. The basis of informed consent is the promotion of patient autonomy. The implications for how informed consent is performed would be different if informed consent were viewed more as a social interaction than a legal and bureaucratic obligation. [4]
We suggest that accountability should incorporate the form and performance of ritual within the research process to render ethical practices visible to participants. Many researchers may already be applying research processes that call for iterative generative engagement with communities. However, the ethical component of respectful community engagement that this represents has to be made explicit in researcher IRB applications, applications for funding, research proposals and perhaps most importantly with students involved in research (NAIDU & SLIEP, 2011). We recommend reforming the processes of reviewing member checking, returning results and dissemination as accountability practices rather than as validity practices. This process would involve paying attention to re-presenting results in ways that are meaningful or make sense to participants and can contribute in part to reducing the power differential between researchers and participants (CHAMBERS, 2014; GUILLEMIN & GILLAM, 2004; MADER, 1999). Accountability in these processes might also be included as criteria for ethics review boards to consider in reviewing research proposals. This kind of accountability compels engagement and reciprocity with participants and reflexivity from researchers at multiple stages in the research process. [5]

At the same time, it is important to consider the converse, which is that it is often assumed in social science research and in the debate on research ethics that researchers are in a position of power. BRADSHAW's (2001) research presents the alternative possibility of corporates or governments who are powerful in comparison to researchers. In this case we propose that accountability practices may serve to increase trust and cooperation through consistent member checking, returning results at discussed intervals and formats as well as early negotiation of how returning results and dissemination will ultimately unfold. We advocate for a clear plan, purpose and process for member checking, returning results and dissemination. All of these, usually terminal research activities, may be classified under the umbrella of accountability practice or taking-it-back practices. We consider whether accountability or taking-it-back practices should be treated as single events or an ongoing process where the researcher constantly checks emerging findings with participants to keep the research process authentically and ethically on track (MACLEOD, MASILELA & MALOMANE, 1998). [6]

STEIN and MANKOWSKI (2004) critically examine the assumption that qualitative research serves to reveal or amplify the voices of participants. They explore connections between qualitative research and social change and describe the use of qualitative research to not only empower marginalized groups but also critique and transform privileged groups. Qualitative research activities are a series of interrelated acts including asking, witnessing interpreting knowing. The framework is intended to help community researchers to more fully conceptuizalize, understand, and engage in the practice of qualitative research. In STEIN and MANKOWSKI's view witnessing encompasses "listening to and affirming the experiences of research participants" (p.22). The focus of witnessing is on acceptance of the participants' voice and accountability for acting upon it, "not on the personal needs of the researcher or a desire of mutuality between researcher and participant" (p.24). It is from this perspective that the
term accountability practice better describes the intentions of the process and influences the practices that it entails. [7]

In this paper we illustrate the influential metanarrative of accountability that we maintained to engage with the community organization to hold ourselves answerable in representing their work authentically (BRADSHAW, 2001). We present the example of a project in which we implemented an accountability perspective to member checking, returning results and dissemination. In the case study our role as researchers was to document and describe the activities of a community-based organization that provided social and health care and support to a resource constrained rural community. We worked closely with members and leaders of the organization to verify that we were authentically representing their activities as well as the descriptions scope and ethos of the organization. [8]

2. The Study: Performing Accountability Practices

2.1 Context and background

The community under attention in this study is a well-established non-governmental organization (NGO) functioning for over 15 years within a rural community in KwaZulu-Natal, South Africa. The organization provides basic healthcare service, social welfare support, legal advice, home-based care, early childhood education and support, health education and support groups for HIV and AIDS affected persons amongst other various health, social and basic legal services. The NGO was founded and continues to be managed by three women. Two are local women and the third became associated with the community through her volunteer work with a local Buddhist Retreat Center (BRC). The researchers encountered the NGO through their association with the BRC. PROSE noticed that a distinctive feature of the NGO was the used of mindfulness-based and reflective practices during meetings and as part of their staff support practice. A second distinctive feature of the organization was its longevity as a community-based organization as well as the fact they managed to retain staff consistently for a long period of time. The latter is an unusual feature in community care organizations in South Africa. In general community care organizations tend to have poor longevity because of funding constraints and inconsistent management and high turnover of care staff attributable to difficult and demanding work conditions (AKINTOLA, 2008). Moreover community caregivers used such work as a means of access to paid work in the health industry leading to high attrition as community caregivers obtain work high wages in government or private healthcare organizations. In discussions with the leaders, community health workers and community members and from observations of the group and some limited participation in their activities, we came to realize that there were various practices that the organization engaged in that seemed to contribute to their success and longevity as an organization in the community. The researchers and NGO leaders agreed that it would be useful to describe and document the NGOs activities and processes to share their experiences and learning. The NGO members and community were agreeable as they felt that publicizing their work would increase their chances of securing
funding which the organization relied on for its survival. We decided to 1. look at what mindfulness and reflective practices were employed within the organization; 2. discover the ethos underpinning these practices; 3. explore how mindfulness and reflective practice originated within the organization; 4. determine how these methods were used in the organization contribute to the success and longevity of the organization; and 5. explore how members of the organization saw reflective practices as contributing to their personal and professional development and the growth and the sustainability of the organization. [9]

Members and leaders of the organization seemed to take the mindfulness and reflective methods that they used for granted. They saw it merely as a practice that worked to bring them together, strengthen bonds and alleviate some of the stresses they experienced in their work. In discussions with the members we began to realize that the success in terms of staff retention and longevity of the organization was due in no small part to the culture of mindfulness and reflection that was encouraged and promoted amongst all members of the organization. Community health workers on the staff used the practice in their own lives and work and took it to the community through the people they worked with. These practices included guided meditation, body scans, relaxation, reflecting on their work in groups and mindfulness practice. In the process of documenting and preparing to describe the mindfulness-based and reflective methods we realized that it was crucial that the organization and its participants' work be represented on their terms and that they be presented and recognized as experts in how they used mindfulness practice. We set the intention to relegate our role as experts and elevate the participants' role as experts. Here we present the steps we took to approach this intention recognizing that it would be impossible to achieve this in the ideal due in part to our roles as expert researchers despite not being expert practitioners. Ethical clearance for the research was obtained from Duke University and the University of KwaZulu-Natal. [10]

2.2 Research design and process

A community-based qualitative research (CBQR) approach was employed in which the researchers participated in and observed organization activities that used reflective and mindfulness-based practices. This design was selected as the research process was based on documenting the organization's unique mindfulness-based practices with the close participation of its members. The activities in the documenting process included morning meetings, caregiver support groups, management and staff meetings and support groups. Interviews were conducted with administration and management staff as well as facilitators and community caregivers to determine their ideas and experiences concerning these practices. In keeping with the ethically motivated decision to hold the organization and participants as experts of their own practice we decided to establish a multilevel process to ensure that we were documenting the practices as they were intended. On one level this process mirrored the conventional validity processes of member checking, returning results and dissemination. However, we held them under the collective lens of accountability practices and employed iterative strategies among and between processes to ensure that
participants were constantly informed and involved in how we were constructing our understanding of their practices and experiences. [11]

In the next section we unpack the proposed elements of accountability that we refer to as accountability practices. We first consider how the conventional validity procedure of member checking may be used as an accountability practice if it is applied as an iterative-generative process during data collection. Second, we consider how taking results back to the community or participants can constitute a validity practice if the methods and media through which results are presented are interesting and accessible to the community. Finally, we show dissemination can contribute to accountability through close consultation with the community or participants on the formats and contexts how findings are presented to broader audiences. We suggest that these practices should be implemented as interconnected by respectful reciprocity with the participants throughout the research process. [12]

3. Accountability Practices Within the Research Process

3.1 Member checking

Member checking is commonly used to verify the accuracy of data once the researcher has completed collection and possibly analysis of the data (BRADSHAW, 2001; CHANDLER, ANSTEY & ROSS, 2015; HARPER & COLE, 2012). We used member checking as an iterative generative process in this study. Member checking was incorporated as part of the data collection process through two main strategies: first, a specific questioning style employed within semi-structured interviews and focus group interviews and, second, by relying on key informants to facilitate and verify our understanding of ethnographic data as the research process unfolded. [13]

In the process of data collection we employed strategic questioning to uncover the participants understanding and ideas about how reflective practice and mindfulness based practices were used in the organization. These included "interventive" interviewing and Socratic, circular and reflective questioning (TOMM, 1988, p.1). In these methods the interviewer employs a facilitative approach and deliberately asks questions that promote new possibilities for self-understanding. This allows participants to view and represent themselves as part of a system and reflect on how their thoughts ideas and activities are reflective of and reflected in the systems of which they are a part. During observations of groups and ethnographic observation key informants apprised researchers of how support groups were conducted and the processes and practices employed. Member checking was thus incorporated within the data collection through the use of specific questioning and clarification strategies. Cross checking and reflecting with key informants throughout the observation processes promoted our understanding of how mindfulness and reflective practices were used (HARPER & COLE, 2012; TOMM, 1988). For example we attended community support groups for family caregivers, people living with HIV and community caregivers that were facilitated by members of the NGO. During the groups
facilitators demonstrated and explained process and purpose of the group. Following the groups we shared with the facilitator what we had heard and observed of how the groups were taught to use mindfulness based practices and checked with the facilitator whether our understanding aligned with theirs. [14]

3.2 Returning results

We returned results to the group in the form of a "taking-it-back" event during which we presented our understanding of the findings that emerged from the initial phase of the study. Taking-it-back practices or events originate from narrative community practice (AUDET & PARE, 2017). These practices are essentially employed to return results to communities using methods that are relevant and relatable for community members and participants. Such methods may involve drama, storytelling visual presentations, etc. and are motivated by the intention to create positive effects amongst the very community in which the research was conducted (HOLLOWAY & TODRES, 2007; SLIEP & KASIMBASI, 2011; STEWART & DRAPER, 2014). Researchers have noted that there are drawbacks to returning results in the form of written reports as this reduces the impact of results on communities (KEEN & TODRES, 2007). Other drawbacks include having to negotiate whether participants have veto rights over the final interpretation and presentation of data (CLOW, 2005). Also, according to JACKSON and VAN VLAENDEREN (1994) "the knowledge produced in research may be viewed as a social construction, created in the interaction between the researcher(s) and participants from a multiplicity of potential meanings" (p.9). The results that researchers convey might not align with participants' views of the data in context. Results should be returned the community before they are presented in any other forum to ensure that community members are aware of and agree with how they and their communities would be represented by researchers. At this stage community members may support or challenge findings or how they are represented as participants. We acknowledge that different texts, formats or presentations of the data exist for different audiences, namely, scientific vs. community. Our concern here is with how and when data about communities is presented to communities. We elected to return results through a visual presentation that consisted of photographs and video clips that both researchers had taken during the data collection process. We created a narrative supporting the photographs and jointly told the story of how we as researchers and outsiders saw and experienced the NGO and its activities. In the telling of our perspective as researchers we were careful to use language that emphasized that the presentation reflected our understanding and experience of what we documented in the data collected and not objective truths or scientific facts. We encouraged an atmosphere of discussion and clarification so that participants would feel comfortable to offer their responses to the presentation. Prior to presentation we held an initial meeting with the NGO managers for an initial presentation as these three women assisted in translating our presentation to isiZulu to the group during the presentation. On the day of the taking-it-back event all members of the NGO as well as members of the community were invited to the presentation and storytelling. In accordance with local community practice, transport and food was provided to all those attending the event. [15]
Following the event participants reported that they felt that their work was truthfully represented and that the researchers had a realistic picture of who they were and what they were aiming to achieve as an organization. Some participants expressed surprise and gratitude about the careful attention that was paid to recognizing and validating their work. At this stage we reiterated that our understanding and appreciation of their work would be presented in academic forums and reports. The participants were supportive of this and we agreed that all presentations would be available to them prior to presentation to outside parties. In taking this approach to returning results we had the intention, not of empowering the participants, but being respectful of the agency they already demonstrated as we observed and documented their work (DAS, 2009; KARNIELI-MILLER, STRIER & PESSACH, 2009). This agency was evidenced in how they created and conducted the NGO and in the impact and respect they effected in their community. [16]

Returning results and dissemination are often seen as equivalent practices (LAFRENIERE, MENUZ, HURLIMANN & GODDARD, 2013). We distinguish between the two by viewing returning results as taking research findings back to the community in which data was gathered. These findings, presented to the community, constitute researchers' perceptions and understanding of data. The latter is preferably organized and presented in format that is meaningful and useful to the community as our illustration above describes. Alternatively we view dissemination as distributing findings to other social and academic communities. This would typically include related community or academic presentations, research and funder reports and academic publications. Dissemination may be seen as

"a planned process that involves consideration of target audiences and the settings in which research findings are to be received and, where appropriate, communicating and interacting with wider policy and health service audiences in ways that will facilitate research uptake in decision-making processes and practice" (WILSON, PETTICREW, CALNAN & NAZARETH, 2010, p.2). [17]

Bearing the difference needs, contexts and perspectives of the audience in mind, as mentioned the media and messages that they convey are adjusted accordingly (McLUHAN, 1964). [18]
3.3 Dissemination

Our initial dissemination of data from this study was done at a University Global Health Humanities programs event. In this presentation we used professionally edited and compiled videos to present the results of our analysis of the data. Video footage was obtained through a student video project at the NGO and footage taken by a professional documentary filmmaker and volunteer teacher on the project. The documentary filmmaker consulted with the researchers to compile two mini-documentaries. We communicated with participants during the process to verify that our representations were consistent with their perceptions of themselves and the organization. At the participants’ suggestion choral music that they had recorded in another project within the NGO was used as background music for the videos. Once completed the videos were shared with the NGO and placed both on their website and made available on YouTube. For us as researchers this prompted a process of reconfiguring or re-imagining researchers and participants' different perceptions of exposure. As researchers, we were concerned about exposure, confidentiality and risk whereas the participants were focused on exposure, recognition and benefit. This upended our conceptualization of power and agency in and through research and its processes (NAIDU, 2018). [19]

As in the entire process, our intention in the dissemination phase was guided by the needs and desires of the NGO (KARNIELI-MILLER et al., 2009). In the initial stages of the research participants had expressed that they wanted their organization and work to be known as widely as possible. Bearing this mind we worked to present our findings in public forums before preparing the work for presentation in academic settings. This afforded a renewed perspective on the data and how we presented them as we were obliged to first and always consider how they NGO and participants wanted to be represented. It might be argued that this approach could constrain researchers' academic freedom and create a situation in which participants dictate or control how data is presented if they have the capacity and are empowered enough to do so (CLOW, 2005; MACLEOD et al., 1998). We suggest however that under current conditions researchers have an inordinate amount of power around how participants' their lives and experiences are presented. In this context the organization consisted mostly of poorly educated women from groups that were previously disadvantaged in the Apartheid system in South Africa. The researchers were educated people from middle class backgrounds. Despite the group members being empowered in and by their work this social and educational discrepancy between participants and researchers created undeniable if not immediately evident power issues. The terminology used to describe dissemination strategies (diffusion, dissemination, implementation, knowledge transfer, knowledge mobilization, linkage and exchange, and research into practice) implicitly favor funder and researcher conceptualizations of the issues at hand and their goals rather than participants' needs. Underscoring this is that there is a lack of clarity amongst funding agencies regarding what constitutes dissemination (LAFRENIERE et al., 2013; WILSON et al., 2010). This precludes ethical imperatives around dissemination with regard to participant and community needs. [20]
4. Discussion

In this paper we look at member checking, returning results and dissemination not simply as validity checks but consider these activities as accountability practices. The incentive for this revised view is to offer reciprocity in the processes and contexts where research participants, communities and others receive and benefit from research outcomes. Our argument is inspired by the convention of these practices being conducted in a piecemeal and unreflective manner. We propose that linking member checking, returning results or taking-it-back practices and dissemination as related events in the research process which are guided by the ethical principles of respect for persons and autonomy can create the conditions in which each procedure promotes and enhances the other. Accountability should be used as the linking motivation. Here accountability is characterized by respectful reciprocity with participants throughout the research process. [21]

Our case example illustrates how we documented the use of mindfulness-based practices for staff development and support by a community based health promotion organization. We were able to connect and develop trust easily with the community and they were responsive because one of the team was previously familiar with the group. However, in instances where researchers enter a new group or community careful attention must be invested in connecting with participants. Moreover the information that we were documenting was mostly positive. If the research topic in question is a sensitive or contentious issue researchers might encounter difficulties with any or all aspects of the process. Accountability is likely to have different implications, for participants are more wary of exchanging information with researchers if the research topic is more sensitive. In the case of taking-back practices more sensitivity and reflection is called for if, for example, sensitive issues domestic violence in a community is investigated. Finally dissemination also would be affected by the content of the research study. Participants may be more restrictive of how they want results disseminated and researchers could possibly be more reticent about how they consult with participants in planning research dissemination strategies. [22]

Accountability in handling the results of research studies should be a complex and overarching process if the principles of "respect for persons" and "autonomy" are to be upheld. Researchers must plan and prepare whether and how they will check and communicate research findings at the outset of the research process. Post-hoc and fragmentary management can severely impact on accountability. Taking-it-back practices, in particular, must be congruent with needs, expectations of communities and participants if they are to authentically support and be supported by member checking and dissemination strategies. [23]
5. Conclusion

We propose the ethical imperative, in community-based qualitative research, that researchers use member checking, returning results and dissemination as accountability practices. In community-based qualitative research, researchers are typically immersed in the research context, attending to and participating in the daily practices of the community, reflecting on observations and clarifying perspectives such that key informants and community members serve as ongoing member checking sources (BANKS et al., 2013). In the process, community members and key informants begin to understand the researchers' positioning and intent and interact more keenly as trust increases. Taking an accountability perspective to connect the activities of member checking, returning results and dissemination may have the potential to offer researchers an orientation to the process that is reciprocal and respectful.

Taking a reflexive position, we concede that even when researchers take an accountability perspective, there are aspects of the research process that cannot be controlled for. In this case in particular we realize that messages about research findings conveyed by qualitative researchers are influenced by a multitude of factors. The most important of these influences include the audience, media used to convey the message, the context in which the message is conveyed, community perceptions of and relationships with the researchers and the purpose of the research project. We advocate primarily for the revision of the conventional ethical and validity practices of member checking, returning results and dissemination to be connected through a thread of respectful reciprocity such that they become accountability practices.

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References


Banks, Sarah; Armstrong, Andrea; Carter, Kathleen; Graham, Helen; Hayward, Peter; Henry, Alex; Holland, Tessa; Holmes, Claire; Lee, Amelia; McNulty, Ann; Moore, Niamh; Nayling, Nigel; Stokoe, Ann & Strachen, Aileen (2013). Everyday ethics in community based participatory research. *Contemporary Social Science*, 8(3), 263-277.

Birt, Linda; Scott, Suzanne; Cavers, Deborah; Campbell, Christine & Walter, Fiona (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation. *Qualitative Health Research*, 26(13), 1802-1811.


Burke, Wylie; Evans, Barbara & Jarvik, Gail (2014). Return of results: Ethical and legal distinctions between research and clinical care. *American Journal of Medical Genetics Part C Seminars in Medical Genetics, 0*(1), 105-111.


Long, Christopher; Stewart, Kathryn & Mcelfish, Pearl (2017). Health research participants are not receiving research results: A collaborative solution is needed. *Trials Biomed Central, 18*(449), 1-4, [Accessed: September 11, 2018].


McDavitt, Bryce; Bogart, Laura; Mutchler, Matt; Wagner, Glenn; Green, Harold; Lawrence, Sean; Mutepfa, Kieta & Nogg, Kelsey (2016). Dissemination as dialogue: building trust and sharing research findings through community engagement. *Preventing Chronic Disease, 13*(150473), 1-7.

McShane, Kelly; Davey, Caitlin; Rouse, Jennifer; Usher, Amelia & Sullivan, Shea (2015). Beyond ethical obligation to research dissemination: Conceptualising debriefing as a form of knowledge transfer. Canadian Psychology, 56(1), 80-87.

Miller, Tina & Boulton, Mary (2007). Changing constructions of informed consent: Qualitative research and complex social worlds. Social Science & Medicine, 65(11), 2199-2211.


Naidu, Thirusha (2018). To be or not to be ... Revealing questions of anonymity and confidentiality. In Cattriona Macloed, Jaqueline Marx, Phindezwa Mnyaka & Gareth Treherne (Eds.), The Palgrave handbook of ethics in critical research (pp.241-256). London: Palgrave Macmillan.


Sofaer, Neema (2014). Reciprocity-based reasons for benefitting research participants: Most fail, the most plausible is problematic. Bioethics, 33(1/2), 456-471.


Wilson, Paul; Petticrew, Mark; Calnan, Mike & Nazareth, Irwin (2010). Disseminating research findings: What should researchers do? A systematic scoping review of conceptual frameworks. Interpretation Science, 5(91), 1-16.

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