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Strategies for Disseminating Qualitative Research Findings: Three Exemplars

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Abstract: Assuming there are those who do pay attention to the dissemination of qualitative research findings, what can we learn from them? For this article, we searched for examples of qualitative research where findings have been disseminated beyond the journal article and/or conference presentation. The rationale for pursuing examples of how good qualitative research has been disseminated is that we pay attention to both scientific *and* communicative concerns. All three exemplars in this article go beyond the forms of dissemination that traditionally serve academic communities and attempt to address the communicative concern of qualitative research findings. This is not to say that these modes of dissemination replace the scholarship of qualitative research and/or the peer-reviewed journal manuscript—far from it. In disseminating qualitative data, researchers have an array of presentational styles and formats to choose from that best fit their research purposes, such as drama, dance, poetry, websites, video and evocative forms of writing. We conclude by considering the ethical issues that may be involved in these forms of disseminating qualitative research, as well as the challenges for evaluating the impact of such strategies.

Key words: *qualitative research, dissemination, communication, evaluation, ethical issues*

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1. Introduction

Research dissemination, as the written or oral representation of project findings, usually happens at the end of a research project (BARNES, CLOUDER, PRITCHARD, HUGHES & PURKIS, 2003; WALTER, NUTLEY & DAVIES, 2003). In doing so, few authors of qualitative studies move beyond the dissemination of their work in the ubiquitous journal article. Though the number of qualitative projects increases year on year, the implications of this work appear to remain on shelves and have little impact on practice, research, policy or citizens (FINFGELD, 2003; TROMAN, 2001). How does this happen? [1]

Is it because qualitative researchers simply do not wish to make a difference with their work? Or, is it because authors pay attention to the scientific concerns of qualitative research but not the communicative ones (SELLS, TOPOR & DAVIDSON, 2004; TODRES, 2004; WILLIS, 2004)? Maybe it's because funders of research focus on the financial records of research activity and do not track the dissemination status of research projects (MCCORMACK, LOEWEN & JEWESSON, 2005). Perhaps qualitative researchers are blind to the fact that communicating research is now considered an obligation (POTOCNIK, 2005). Or is it simply because modes of dissemination that traditionally serve research communities, such as the journal article or conference presentation, often confine audiences to fellow academics

(BARNES et al., 2003) and generally divorce researchers from practice and action (MULLEN, 2003)? Assuming there are those who do pay attention to the scientific *and* communicative concerns or communication of qualitative research findings, what can we learn from them? The central focus of this paper, therefore, is to point to such exemplars. [2]

In a recent literature review on the impact of research, WALTER et al. (2003) found that, although some studies had used qualitative approaches to evaluate and assess strategies to increase the impact of research in practice, *none* focused on the dissemination of qualitative research findings. Provoked by this finding, we set about our own review of the literature. What follows is a shortened revised version of this paper (KEEN & TODRES, 2006). [3]

2. Background of the Review

Qualitative research, done well, is worth disseminating. The process of communicating qualitative research findings does not appear essentially different from using the findings of any other kind of research (ESTABROOKS, 2001). If findings from qualitative research projects are disseminated, this usually happens at the end of a research project using modes such as a final report, journal article, book chapter and/or conference presentation. Opportunities for discussion, for example around how research findings may apply to the lives of people who use health and social care services, are possible but limited and depend on the journal and/or conference. Put another way, the *active* task of applying research to practice, policy or people is often seen as lying beyond the research process. This active dissemination implies the use of tailored materials that have been transformed, beyond the journal article or conference paper, for targeted audiences, where discussion of the meaning and application of findings is facilitated (WALTER et al., 2003, p.17). [4]

The main features of successful dissemination strategies can, therefore, be summarised as:

- Tailoring approaches to the audience, in terms of the content, message and medium;
- Paying attention to the source of the message;
- Enabling active discussion of research findings (NUTLEY, WALTER & DAVIES, 2002; WALTER et al., 2003). [5]

3. Review Methods

A mixture of well-known education, social care and health databases (n=12) were searched using variations of key terms such as "qualitative" and "dissemination". This process produced a list of 1094 abstracts. At first reading, 51 of these were considered relevant to our aim of seeking examples of authors' paying attention to the communication of qualitative research findings. We had already located some of these references via key journal website searches and by making email contact with known "experts". In total, 62 references were read in full and synthesised using three main headings:

- Topic, context and background;
- Method and mode of approach to dissemination;
- What theoretical and/or empirical difference could it make and to whom? [6]

Analytically, it was clear from this work that these studies could be separated in terms of their scientific foundation and how they were disseminated and evaluated. Therefore, they could be divided into six distinct groups:

- Those authors who had used empirical qualitative studies as a foundation to their dissemination and those who had not;
- Those who had transformed qualitative research findings in order to communicate their work and those who had not;
- Those who had evaluated the impact of their work in some way and those who had not. [7]

Because paying attention to the source of the message had already been identified as important in disseminating research, we focused our review on the 16 references or groups of references using an empirical foundation for their dissemination. Their modes of dissemination were as follows:

- Research-based theatre/ethnodrama/dance (text, performance and video) (BAGLEY & CANCIENNE, 2001; GRAY 2000; GRAY 2003; GRAY, FITCH, LABRECQUE & GREENBERG, 2003; GRAY, FITCH, PHILLIPS, LABRECQUE & FERGUS, 2000; GRAY & SINDING 2002; GRAY, SINDING, IVONOFFSKI, FITCH, HAMPSON & GREENBERG, 2000; MIENCZAKOWSKI, 1995, 1996, 1997, 2003; MORGAN, ROLFE & MIENCZAKOWSKI, 1993; ROLFE, MIENCZAKOWSKI & MORGAN, 1995);
- Poetic texts (GLESNE, 1997; RICHARDSON, 1992);
- Unperformed performance texts (PIFER, 1999; ROGERS, FRELICK & BABINSKI, 2002);
- Evocative writing and story-telling (CLEARY & PEACOCK, 1997; GRAY, 2004; SELLS et al., 2004);
- Multi-media presentations (COLE & MCINTYRE, 2004);
- Patchwork quilts (including audio and photographs) (BRACKENBURY, 2004);
- Documentary film (TILLECZEK, CHEU, PONG & BOYDELL, 2004);
- Website and DVDs (ROZMOVITS & ZIEBLAND, 2004; SILENCE, BRIGGS & HERXHEIMER, 2004);
- Workshops (SMITH, MASTERSON, BASFORD, BODDY, COSTELLO, MARVELL, REDDING & WALLIS, 2000);
- Health promotion brochure (EMSLIE, HUNT & WATT, 2001a, 2001b; HUNT, EMSLIE & WATT, 2001). [8]

We also wanted to find out how far these researchers had tried to assess or evaluate the impact of their dissemination on practice, research, policy or the people it was about. Just three groups of studies went beyond what we called author self-reflection. The next section contrasts these three exemplars. [9]

4. Key Exemplars

The first two exemplars use research-based theatre/ethnodrama to represent qualitative data and are based in Canada and Australia respectively. The third UK-based exemplar uses the Internet to communicate qualitative data. [10]

4.1 Key exemplar 1: "Handle with Care?" and "No Big Deal?"

4.1.1 "Handle with Care?"

In essence, the dramatic production "Handle with Care?" shows "the dilemmas around communicating prognosis to a person with a non-curable disease and takes audiences beyond the preoccupation with techniques and goals, to an empathetic experience with the ill person" (GRAY, FITCH et al., 2000, p.143). It arose out of two qualitative research studies: focus groups with women living with metastatic breast cancer (cancer that has spread beyond the breast) in Ontario, Canada, asking about their information needs; followed by interviews with medical oncologists examining their views on the issues these women had raised as being important. "Handle with Care?" was not a planned outcome at the outset of the above studies. Instead, the research team tested out the potential of research-based theatre to accurately represent qualitative research findings. To do this, GRAY forged a partnership with a theatre group for older adults at a local university which provided leadership in developing the first draft of this dramatic production (GRAY, 2000). Importantly, women with metastatic breast cancer were also involved in this partnership as investigators and consultants. This partnership worked on thematic analysis, script development and numerous improvisation exercises for

over six months (GRAY, FITCH et al., 2000). Most of the words for the "Handle with Care?" script were taken directly from the transcripts of the two studies. [11]

"Handle with Care?" was piloted to audiences of service users and physicians and changes were then made before it was performed in all eight Ontario cities hosting a regional cancer centre. By the year 2000 they had made around 200 presentations throughout Canada and the United States (GRAY, 2000). Two versions of "Handle with Care?" exist—one for health professionals and one for the general public (GRAY, FITCH et al., 2000). Evaluation questionnaires were sent out to general public attendees in seven Ontario cities—507 service users and family members (between 60-70% of the total audience) returned them complete. All agreed that they had enjoyed the production and had benefited from seeing it. Nearly all said the drama had "a lot of truth" in it and expressed a desire to see further productions about living with cancer. Further feedback from 249 health professionals (between 40-50% of the total audience) showed that the use of research transcripts had increased the validity of the presentation and that it engaged them. Nearly all of the samples stated that the issues presented were relevant and useful for thinking about their clinical practice. A video of the "Handle with Care?" and "No Big Deal?" performances are included with the book *Standing Ovation* (GRAY & SINDING, 2002; please see Mary GERGEN's [2003] review of [Standing Ovation](#)). [12]

4.1.2 "No Big Deal?"

"No Big Deal?" is another dramatic production, structured as a series of vignettes portraying the shock of diagnosis, coping with impotence and many other challenges facing men with prostate cancer and their wives (GRAY et al., 2003). It is based on separate interviews with men (n=34) and their wives before the men had prostate surgery, two months after surgery, and a year later; several urologists were also interviewed. In contrast to "Handle with Care?", the explicit aim of "No Big Deal?" was to increase awareness about issues relating to prostate cancer by using research findings to engage service users and health professionals. As before, this project used a partnership group to create the dramatic script, consisting of researchers, men with prostate cancer and their wives, actors and a scriptwriter. Transcripts were coded, discussed and analysed, and improvisation classes were introduced to explore the depth of major themes before a draft script was written. Again, most of the words used in the script are drawn from interview transcripts. Trial presentations were made to health professionals, service users and theatre experts, and subsequent revisions were made to the script. "No Big Deal?" has been performed over 70 times at conferences, cancer centres, community gatherings and in workplaces throughout Canada. It lasts 40 minutes and is followed by a 15-minute facilitated discussion period. It is therefore designed to fit into a one-hour time-slot for a hospital round or lunch break. [13]

Self-selecting health professionals, including physicians, nurses and care staff (n=26), were asked in advance of a "No Big Deal?" performance whether they would take part in three telephone interviews—before they saw the production, within two weeks of attending and six months later. Many reflected on having gained a new level of awareness and understanding from "No Big Deal?", most often related to how service users are affected by diagnosis and treatment. Health professionals also commented on the humanising effects of engaging with lives on stage—this allowed increased insight and empathy. In addition to bridging the worlds of research and theatre, GRAY (2000) has fundamentally shifted the way he thinks about himself as a researcher. As he explains,

"research-based theatre represents another attempt to come to terms with issues such as: the nature of knowledge construction, considerations about how to best honour and represent others' voices, concerns about truth and validity, and especially the desire to have research make a difference in the world" (p.377). [14]

As such, GRAY references Jim MIENCZAKOWSKI and the following two ethnodramas, "Syncing Out Loud" and "Busting". [15]

4.2 Key exemplar 2: "Syncing Out Loud" and "Busting"

Both of the following works were born out of a desire to join theatre with ethnography to create educational potential that could help disempowered health consumers gain a voice (MIENCZAKOWSKI, 1995, 2003). Therefore, MIENCZAKOWSKI sought to use research and the public performance of it to give insight into the lives of those who have become marginalised and disempowered through their health experiences (MIENCZAKOWSKI, 1997). [16]

4.2.1 "Syncing Out Loud": A journey into illness

This is a "pilot" drama reflecting the schizophrenic illness where individuals think out loud but lack synchronisation in their thought processes. The aim was to help audiences better understand mental health problems by creating an experience of psychosis (MIENCZAKOWSKI, 2003). The drama was compiled from an intensive and prolonged period researching experiences of psychosis and schizophrenic illness and attitudes towards courses of treatment (MIENCZAKOWSKI, 1995, 2003). This involved participant observation and informal interviews within an Australian state secure psychiatric unit and day centre (MIENCZAKOWSKI, 1996). The content of the drama relied on this work and included themes such as the lack of public support and understanding for sufferers of schizophrenia and the impact of medication (ROLFE et al., 1995). Each stage of data collection, scripting and performance was subject to informant validation (MIENCZAKOWSKI, 1995, 2003). [17]

The resulting drama is set during a fictitious psychiatric care conference where delegates present papers defining mental health and community issues surrounding schizophrenia (MORGAN et al., 1993), while simultaneously following the experiences of a newly diagnosed sufferer (ROLFE et al., 1995). Each audience member is given a photographed name badge with key character names to allow them to "step out from themselves" (MORGAN et al., 1993 p.268). The drama was performed by nursing students and actors in university and residential psychiatric settings to service users and health professionals. Each performance was followed by a recorded forum of audience and cast, thereby providing further study data (MIENCZAKOWSKI, 1995, 1996, 2003; ROLFE et al., 1995). Psychiatric nurses and counsellors were on hand throughout performances, and copies of the script and literature relating to support agencies were also available (MIENCZAKOWSKI, 1996). [18]

Feedback on "Syncing Out Loud" was also gained from interviews with nursing staff and student nurses, voluntary written responses, small structured group work, and student nurses' personal journals and reflection papers (MORGAN et al., 1993; ROLFE et al., 1995). Thematic analysis of this data showed how students developed considerable awareness of issues surrounding this schizophrenic illness through role play, clinical experience and involvement in the play (ROLFE et al., 1995). While those taking part in debriefing groups agreed the play was worthwhile and had generated meaningful discussion among health professionals and service users, the most cathartic moment for the authors was when the audience invaded the stage at the play's conclusion, demonstrating their "relatedness" and wanting to tell their own stories (MORGAN et al., 1993). [19]

This pilot project reworked and fictionalised informant experiences and then sought validation from them. However, the second project, "Busting", adapted verbatim narrative into a drama using only fiction to link the script or give an audience increased understanding (MIENCZAKOWSKI, 1995, 2003). Indeed, project informants felt the play only had credence if the audience understood that the play's authority rested on its research status (MIENCZAKOWSKI, 1996). The project aimed to research, explain and inform audiences about health issues surrounding alcoholic abuse by presenting the experience of ending a period of sobriety, hence the use of the term "Busting" (MIENCZAKOWSKI, 1995, 1996, 2003). [20]

4.2.2 "Busting": The challenge of a drought spirit

This is based on data gathered by ethnographers, unit staff, actors and nursing students via participant observation and interviews over a four-month period in an urban detox unit (MIENCZAKOWSKI, 1995, 2003). This data revealed the stigmatisation that service users and health workers feel, how detox is viewed as a "Cinderella" service ("Cinderella" means left out)

and the importance of gender issues, for instance with reactions of male clients to female carers and co-workers (MIENCZAKOWSKI, 1995, 2003). During this phase, data reduction and script development was fed back to service users, actors, researchers and healthcare professionals for consensual amendment and validation (MIENCZAKOWSKI, 1996, MIENCZAKOWSKI & MORGAN, 2001). Service users were involved in the rehearsal process to guide actors (MIENCZAKOWSKI, 1996). The final validating audience for "Busting" included general practitioners, service users, academics, health administrators, human resource officers, nurses and care-givers (MIENCZAKOWSKI, 1996). Post-performance recordings of cast and audience discussions continued the process of script revision (MIENCZAKOWSKI, 1996). [21]

"Busting" has been performed to service users, community drug and alcohol agencies, high school students and the general public in clinical, university, school and conference settings, and included health promotion activities such as alcohol impairment tests (MIENCZAKOWSKI, 1995, 2003). As before, scripts were made freely available to audiences and counsellors were on hand (MIENCZAKOWSKI, 1996). In addition, schools were sent support materials for follow-up lessons (MIENCZAKOWSKI, 1995, 2003). These performances received press and television coverage, provoking responses from health service agencies on the issues the play raised (MIENCZAKOWSKI, 1995, 2003). According to MIENCZAKOWSKI (1996), student nurses gained the greatest insight; many expressed a profound change in their understanding of those coping with alcoholic withdrawal. [22]

4.3 Key Exemplar 3: DIPEX

DIPEX, the database of personal experiences of health and illness, was launched in 2001. The primary aim of this project is to describe, from a patient's point of view, many of the 3,000 medical subject headings and therefore provide a rich information source for patients affected by disease and those who look after them (HERXHEIMER, MCPHERSON, MILLER, SHEPPERD, YAPHE & ZIEBLAND, 2000; YAPHE, RIGGE, HERXHEIMER, MCPHERSON, MILLER, SHEPPERD & ZIEBLAND, 2000). Each chosen subject heading is called a module and each module displays differing aspects of an individual's experience; from symptoms to initial diagnosis, to any treatment and possible side-effects, through collections of clips from interviews presented in audio, video and written form (see <http://www.dipex.org/>). These modules, for example on breast cancer or living with dying or depression, are based on a maximum variation sample of face-to-face interviews, where interviewees are encouraged to tell their story with as few interruptions from the interviewer as possible (ZIEBLAND, 2004). These stories are divided into relevant topics and themes and placed on the website. This allows a user to have passive access to the experiences of others, but does not require the user to engage with them in return. The website combines the presentation of these interviews alongside frequently asked questions, reliable medical information, support group contacts and other useful resources (HERXHEIMER et al., 2000). [23]

The underpinning rationale for this work assumes that when people face a new diagnosis or health dilemma, they do not know how to access the information they need, doctors find it difficult to discuss some aspects of disease, and patients telling their story, analogous to when they give blood, have a sense of altruism and solidarity with others (HERXHEIMER et al., 2000). [24]

4.3.1 Evaluation of DIPEX

Two studies have endeavoured to assess the impact of DIPEX to date. In the first, 13 people with hypertension were recruited via a local newspaper advert to search the Internet for four, two-hour sessions at Northumbria University (SILLENCE et al., 2004). Participants spent the first hour online, logging their thoughts and opinions of websites, and the second hour taking part in a group discussion about the role of the Internet in health advice. Participants found the DIPEX site well laid out and easy to search, commending the audio and video links and question and answer sections. The website was valued as a UK website—it presented many genuine personal experiences in that it offered information that participants could not find on more medically oriented websites. Several participants felt empowered after coming into con-

tact with these personal experiences and planned to revisit their general practitioners or family physicians. [25]

In the second study, 28 purposively selected individuals from breast and prostate cancer support groups were recruited to four focus groups (ROZMOVITS & ZIEBLAND, 2004). From these, eight one-to-one interviews (two from each focus group) were conducted to ask about specific cancer information needs. Interviewees were then shown the appropriate DIPEX module and asked whether it would have fulfilled these unmet information needs. A short semi-structured interview schedule was used to elicit their views about the website. The clips discussing experiences of side-effects, recovery, time in hospital and emotional issues were all highly valued; if interviewees had been able to access this type of information, it would have encouraged them to be more active in their decision making. Of the 16 information needs described in both focus groups and interviews, 10 were already covered by the website; the remaining six were planned to be met. [26]

5. Discussion

All three exemplars go beyond the forms of dissemination that traditionally serve academic communities and attempt to communicate qualitative research findings in a meaningful way to the people the research is concerned with. This is not to say that these modes of dissemination replace the scholarship of qualitative research and/or the peer-reviewed journal manuscript—far from it (MORSE, 2004). In communicating qualitative data, researchers have an array of presentational styles and formats to choose from that best fit their research purposes (SANDELOWSKI, 1998). These include drama, dance, poetry, song, painting and evocative forms of writing, as well as animation, diagrams, metaphors, electronic user groups, websites, health education messages, films, photographs, videos, CDs, DVDs, audio-tape recordings and other uses of electronic technology and popular media. The key point is to choose the most appropriate mode of communication for displaying particular qualitative research findings (SALDANA, 2003); in other words, tailoring an approach to the intended audience (NUTLEY et al., 2002; WALTER et al., 2003). [27]

In paying further attention to the communication of qualitative research findings, we are compelled to re-examine the meaning of, and explore the edges of, research (EISNER, 1997; RAPPORT, WAINWRIGHT & ELWYN, 2005). RAPPORT et al. (2005) suggest how researchers prefer their work to be: "laid out in conveniently demarcated areas. Disciplines have their boundaries and crossover between them is problematic. We have our own paradigms and methods, and attempts to introduce interdisciplinary collaboration across paradigms cause discomfort" (p.38). [28]

To illustrate, the modes of dissemination mentioned in paragraph 26 are more closely associated with media and art genres. Arts-based methodologies are usually more visual than textual. Are there distinctions between art and research? If so, what do they mean for the communication of qualitative research findings? Where, for example, should we draw the line when using imaginary tales or fiction alongside empirical data to communicate qualitative research findings? The topic of dissemination raises complex questions, not least around how to evaluate such work. [29]

Using drama and the Internet to disseminate qualitative research findings requires expertise, be it technological or theatrical. Indeed, almost all the modes of dissemination mentioned require some sort of capability. For instance, Laurel RICHARDSON'S (1992) three-page poem about an unmarried mother required her to learn about poetic devices such as repetition, off-rhyme, meter and pauses. For GRAY (2000) and MIENCZAKOWSKI (1995), their projects called for collaborative efforts between researchers, actors, scriptwriters and those the research is about. [30]

Drama in particular is used by two of the exemplars to translate the traditional research report for a wider audience. The essence of drama resonates well with work in health and social care, both being based on roles, performance and ritual (MORGAN et al., 1993). Drama also connects to the full range of sensory experiences often present in original data collection

(GRAY, 2000). DIPEX modules translate research findings to a lesser extent, by "chunking" individuals' narratives into descriptive topics and themes. Nevertheless, the power of these modules and related peer-reviewed publications lies in remaining true to the narrative of the individual. [31]

"Handle with Care?", "No Big Deal?", "Syncing Out Loud" and "Busting" all rely heavily on verbatim data collected using qualitative methods. Fictional narrative is used only when deemed necessary. Indeed, "Syncing Out Loud"'s informants insisted the play only had credence if the audience understood its scientific basis (MIENCZAKOWSKI, 1996). Therefore, alongside tailoring approaches to the audience, the significance of paying attention to the source of the message (NUTLEY et al., 2002; WALTER et al., 2003) is also confirmed by work disseminating qualitative findings. This accuracy, or remaining true to those the research is about, is presented as more important than the mode of dissemination; yet an accurate portrayal is not necessarily an ethical one (MORGAN, MIENCZAKOWSKI, & SMITH, 2001). [32]

5.1 Ethical issues

Not all research may be suited to particular modes of presentation, such as exploring suicide or child abuse through drama. Although little has been written about the ethical considerations of modes of dissemination such as drama, the following note of caution is highlighted: "We urge our colleagues who are considering embarking on health related dramatic performance to be wary, lest they find themselves swamped by the deluge of waves of self-delusion in the guise of professional insight." (MIENCZAKOWSKI, MORGAN & SMITH, 2001, p.193) [33]

The same applies to other modes, such as the Internet. Failure to consider the ethical issues around informed consent and the potential risks to those involved can, quite literally, be fatal (MORGAN et al., 2001). Engaging with ethical issues is positive, however. Our three exemplars focus on serious health and social care issues such as cancer and psychoses. Such conditions, particularly ones that affect marginalised and/or disempowered groups, appear well-suited to modes of dissemination that go beyond the journal article and/or conference presentation. [34]

5.2 A further challenge: the extent of evaluation of impact

Little endeavour has been made to assess the impact that dramas like "Busting" may have (MIENCZAKOWSKI et al., 2001); instead, authors appear better at reflecting on how these processes have fundamentally altered the way they engage with research (BAGLEY & CANCIENNE, 2001; GRAY, 2000; RICHARDSON, 1992). DIPEX has yet to go beyond recruiting individuals from newspaper advertisements and support groups to assess its impact on actual users. Moreover, all of the exemplars have the potential for use in health and social care education, but we could find no instance of where the use of qualitative research findings had influenced educational curricula. [35]

Action research processes may have much to offer the progression of using qualitative research findings and the evaluation of any impact. Partnership with informants, students, practitioners, policymakers, researchers, academics, service users and citizens is woven into the very fabric of the three exemplars. For example, active, facilitated and analysed discussion periods followed performances of "Handle with Care?", "No Big Deal?", "Syncing Out Loud" and "Busting". The qualitative literature also confirms the importance of active discussion about research findings, as well as tailoring approaches to the intended audience and paying attention to the source of the message. The process of communicating qualitative research findings does not appear any different from using the findings of any kind of research (ESTABROOKS, 2001). Successful dissemination strategies are more likely to be ethically considered, piloted and collaborative in nature. As such, they cry out for rigorous evaluation. [36]

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