Communicating qualitative research findings:
An annotated bibliographic review of non-traditional
dissemination strategies

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Introduction

Few authors of qualitative studies move beyond the passive dissemination of their work in, for example, peer-reviewed journals. The number of qualitative projects increases year on year, yet 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? 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 et al. 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 et al. 2005). Perhaps qualitative researchers are deaf to the call that communicating research is an obligation (Potocnik 2005). Could it be because research assessment exercises concentrate on traditional methods of dissemination and not on the impact of research? Or is it simply because these traditional methods 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 communication of qualitative research findings, what can we learn from them? For this publication, we searched for and reviewed literature focused on the dissemination, as distinct from the implementation, of qualitative research findings within health, social care and education sectors.

What follows is divided into seven further sections. The first two cover the *background* information needed to understand the *methods* used in carrying out this review. Next, *an evaluative framework* explains how we asked questions of those studies chosen for more detailed review. This is followed by a section describing three studies that we believe exemplify innovative ways of disseminating qualitative research. A brief *discussion* of what has gone before precedes the usual *references* and *appendices*. The *references* section is followed by an *annotated bibliography* including summaries of relevant texts.

This publication is not a 'systematic' review in the Cochrane sense of an extensive and exhaustive search for literature. Nor does it contain in-depth discussion on how you might go about making decisions about what or what not to disseminate. Work that tries to give guidance in assessing the quality of qualitative research is plentiful (for example, see Dixon-Woods et al. 2004; Murphy et al. 1998; Pawson et al. 2003; Spencer et al. 2004; Waterman et al. 2001). We recognise the difficulty of

answering 'with any precision the question of what constitutes good evidence from qualitative studies' (Dixon-Woods et al. 2004 p.7). Neither do we go into any depth on how qualitative researchers have tried to tackle the general 'so what?' question often laid at the door of their work. For instance, some use action research processes to facilitate action, change and/or understanding (Dick 2002; Meyer 2000; Waterman et al. 2001). Others use qualitative systematic reviews to posit that collectively analysed and interpreted qualitative research findings are more powerful than those from a single study (e.g. Campbell et al. 2003; Paterson et al. 2001), even though you'll find no example of aggregated qualitative research findings disseminated beyond a journal article. Finally, this publication does not focus on the implementation of broader policy studies, except where they are based on qualitative research findings.

However, what we do provide here is a partial picture of how qualitative research findings are currently communicated, based on our existing knowledge of the field, contact with experts and an analysis of database and website search results. Further work is required to make sure other fields of enquiry have not been overlooked and to this effect we make a call towards the end of the review to be furnished with further scholarly examples of how qualitative research findings have been disseminated (using non-traditional methods of communication).

Background

Qualitative research, done well, is worth disseminating. The rationale for pursuing examples of how good qualitative research has been communicated was because they pay attention to both the scientific *and* communicative concerns of qualitative research (Sells et al. 2004; Todres 1998; Willis 2004). In short, their aim is to make more of a difference to the lives of the people the research is about. But why is this review concerned only with research of a qualitative nature? The answer is that previous cross-sector literature reviews focusing on the impact of research in general have been unable to locate studies, specifically or in detail, that address the dissemination and implementation of qualitative research findings (Walter et al. 2003). Even sources that consider the use of qualitative research appear to make no attempt to search the literature for examples of its impact (Morse et al. 2001). Dissemination, as the written or oral representation of research findings, usually happens at the end of a research project (Barnes et al. 2003) and is part of utilisation – utilisation addresses the gap between what we know and do (Nutley et al. 2002). Implementation refers to the use of strategies to change behaviour in specific settings. So, what is currently known about disseminating and implementing research in general?

Existing knowledge about dissemination and implementation

Social care, health and education literature is replete with terminology describing getting research out to a wider audience. This field is complex and poorly understood (Estabrooks 2001). Terms such as dissemination, innovation diffusion, technology transfer, knowledge utilisation, research utilisation and knowledge transfer abound. Many of these terms are included in manuscripts that specifically concentrate on the implementation of evidence-based or evidence-informed practice. This literature often tries to identify a research–practice gap; that is, where evidence in a particular field could be translated to effect changes in behaviour (Nutley et al. 2002). Others might call this the 'deficit' model of communication (Elliott & Popay 2000) i.e. once a gap is found, researchers aim to fill it with whatever is required.

A number of prerequisites appear necessary to utilise research findings (Estabrooks 2001). These include studies of sufficient quality, existence of appropriate synthesis methods and sufficient sector capacity to receive such research messages. Estabrooks (2001, pp280-281) goes on to cite six major assumptions about research utilisation:

- Innovation is good
- Good workers use research
- Research utilisation results in an improved situation

- The dominant efficient choice perspective
- Change is planned
- Knowledge needed for practice is scientific in nature.

These assumptions are, of course, not necessarily valid ones.

Current dissemination and implementation practices

But, how do we disseminate research at present? In the UK, a recent study assessed the potential and actual coverage of Economic and Social Research Council funded social work and social care research projects. '*We don't do dissemination*' was one principal applicant's response (Shaw et al. 2004 p.13). Put another way, the active task of applying research to practice, policy or people is often seen as lying beyond the research process. However, there appears

> 'little point increasing the rate at which research flows to the social care workforce: little research can be directly applied to practice, many practitioners are not equipped to digest research and appropriate support systems are lacking' (Walter et al. 2004 p.2).

Even in sectors like health, where support systems appear better, evaluations of National Health Service Research and Development programmes show that, although the quality of research may be rising, its full effect is unclear (Hurst 2002). What is clear is that there is a major agenda for how utilisation and transfer bridges are made in the social care (Shaw et al. 2004), education (Troman 2001) and health (Hurst 2002) sectors.

Nutley et al. (2003) examined 5,800 references across education, social care, criminal justice and health sectors, with the aim of characterising models and strategies for research impact. They selected 341 of these predominantly 'quantitative' references for detailed analysis (60% were from the health sector) and presented 27 practices aimed at increasing the impact of research, broken down under the following headings:

- Tailored presentation of research findings and the tailoring of research to users' needs
- Increased communication between researchers and users
- Supporting, rewarding and reinforcing the development of research-informed practice
- Staff development, education and training (Nutley et al. 2003 p.14).

Some practices appear more successful than others. The tailored presentation of research includes the use of guidelines, reports, policy reviews, summaries, newsletters, demonstration projects, long-term

research planning and programmes. These may increase awareness and change attitudes but are unlikely to lead to changes in behaviour without the use of mass media and the active discussion of research findings in, for example, workshops or seminars. Therefore, a distinction is made between 'enlightenment', which is the conceptual value of research to bring changes in knowledge, understanding and belief, and 'engineering', the value of directly changing behaviour in policy or practice. Much of the literature, in particular that from the health sector, concerns the latter (Nutley et al. 2003).

Research dissemination may be passive or active. Passive dissemination is defined as a form of communication such as publication in an academic journal; and active dissemination as the tailoring of research findings to a target audience using a dynamic flow of information (Walter et al. 2003). There is no positive or negative evidence as to the effectiveness of the passive dissemination of research. Guidelines were only found to effect changes in practice when they were linked to strategies such as reminders, peer review, marketing and educational interventions, and there is reasonable evidence for the use of mass media, for example television, video, radio and newspapers, to encourage positive behaviour change (Walter et al. 2003). Multifaceted interventions appear to offer the best hope of promoting behaviour change, yet this assertion is at a theoretical level (Bradley et al. 2005; Walter et al. 2003). Although Walter et al. (2003) suggest that it is important to translate research into formats tailored to potential consumers, simply presenting findings in these different formats appears unlikely to change behaviour. The main features of successful dissemination strategies are 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 et al. 2002; Walter et al. 2003).

Although Walter et al. (2003) found some studies that 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 per se. Bradley has, however, led a review of qualitative literature reporting on educational interventions for evidence-based practice (Bradley et al. 2005). Of the 47 studies, just six met sufficient methodological criteria for the review. As with the findings of most quantitative reviews on getting research into practice, multiple interventions appear to offer the best hope of promoting behaviour change. To date, the process of communicating qualitative research

findings does not appear essentially different from using the findings of any kind of research (Estabrooks 2001).

Summary

To summarise this background section, previous cross-sector literature reviews focusing on the impact of research in general have been unable to find studies, specifically or in detail, that address the dissemination and utilisation of qualitative research findings (Walter et al. 2003). The full effect of research is unclear (Hurst 2002). There are no 'magic bullets' to ensure that knowledge from research is used in practice. However, the main features of successful dissemination strategies include active discussion and paying attention to both the source of the message and the intended audience (Nutley et al. 2002; Walter et al. 2003).

The central focus of this review, therefore, was to look for studies addressing the dissemination of qualitative research findings, particularly where non-traditional forms of dissemination are used to communicate qualitative data. We turn now to the review methods used.

Review Methods

A mixture of well-known education, social care and health databases (n=12) were searched in late 2004 using variations of key terms such as 'qualitative' and 'dissemination'. This process produced a list of 1,094 abstracts. At first reading, 51 of these were considered relevant to our aim of finding examples where qualitative research findings had been disseminated. We had already located 21 of these references via key journal website searches (n=7) and by making email contact with 46 researchers: through the Cochrane Qualitative Research Methods Group mailing list, by searching the National Research Register and by contacting known colleagues. At this stage, most abstracts, papers or reports were rejected for review for either not fitting our definition of qualitative research or not being concerned with the dissemination of qualitative research findings. Exact details are contained in Appendix 1: Database search results. Qualitative research is an umbrella term covering many different traditions and is therefore difficult to define. We defined it in broad terms: as a systematic approach to presenting the human and social world, and perspectives on that world in terms of the concepts, behaviours, perceptions and accounts of the people it is about (Ritchie & Lewis 2003).

In total, 62 references from this literature search were read and synthesised onto A4 charts 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?

From this work, it was clear that studies could be separated into six distinct groups:

- Those who had used empirical work as a foundation to their dissemination and those who had not
- Those who had used non-traditional modes of dissemination to communicate their work and those who had not
- Those who had evaluated the impact of their work and those who had not.

By examining these 62 studies in terms of the scientific foundation of the work, and how it was disseminated and evaluated, we were able to design an evaluative framework to place the abstracted contents of the above charts under four main headings:

- Empirical qualitative findings
- Non-traditional mode(s) of dissemination
- Other forms of utilisation
- Evaluation.

The next section explains this evaluative framework in more detail, (shown in Appendix 2) and demonstrates how few references record information under each heading.

- Empirical qualitative findings
- Non-traditional mode(s) of dissemination

An Evaluative Framework

To give an overview, about half the 62 texts reviewed originated from North America, a third from the UK, nine from Australia and one from Finland. Most had a broad health and social care orientation and about a fifth had an educational background. Based on an initial review of these texts, we designed an evaluative framework using four headings:

- Empirical qualitative findings
- Non-traditional mode(s) of dissemination
- Other forms of utilisation
- Evaluation.

Empirical qualitative findings

Because paying attention to the source of the message had already been identified as important in disseminating research, we decided to focus the review on work that used empirical qualitative data as its foundation. For instance, Barnes et al. (2003) wrote a peer-reviewed text deconstructing dissemination as a concept – with no empirical data here, this study did not have any information placed under the 'empirical qualitative data' heading (see Appendix 2). In comparison, Bagley & Cancienne's (2001) article contains an entry under 'empirical qualitative data' as they interviewed parents of UK children with special educational needs about their school choice policy (see Appendix 2). Sixteen texts or groups of texts were classed as being based on empirical qualitative data – broadly speaking, ten came from health and social care (mental health, cancer, heart disease and care in general) and six from education.

Assessing whether a study is based on empirical qualitative data can be problematic and evokes questions such as what is (qualitative) research and how do you make decisions about what or what not to disseminate? At this stage, therefore, no study was rejected for further review on the basis of quality.

Non-traditional mode(s) of dissemination

The second column or heading details the non-traditional modes that the authors used to disseminate their work. Again, taking Bagley & Cancienne's (2001) study, the authors transformed the analysis of their interviews into performed words and choreographed movement, hence the entry 'performed words and movement (dance)' under the appropriate column in Appendix 2. Based on the 16 texts or groups of texts with empirical foundations, we now list their non-traditional modes of dissemination.

- **Research-based theatre/ethnodrama** (text, performance, audio and video) (Gray 2000; Gray 2003; Gray, Fitch et al. 2000, Gray et al. 2003; Gray & Sinding 2002; Gray, Sinding et al. 2000; Mienczakowski 1995, 1996, 1997, 2003; Morgan et al. 1993; Rolfe et al. 1995)
- **Three-dimensional multi-media presentations** (Cole & McIntyre 2004)
- **Dance** (Bagley & Cancienne 2001)
- **Workshops** (Smith et al. 2000)
- **Patchwork quilts** (including audio and photographs) (Brackenbury 2004)
- **Unperformed performance texts** (Pifer 1999; Rogers et al. 2002)
- **Evocative writing and story-telling** (Cleary & Peacock 1997; Gray 2004; Sells et al. 2004)
- **Documentary film** (Tilleczek et al. 2004)
- **Website and DVDs** (Rozmovits & Ziebland 2004; Sillence et al. 2004)
- **Health promotion brochure** (Emslie et al. 2001a, 2001b; Hunt et al. 2001)
- **Poetic texts** (Glesne 1997; Richardson 1992).

Other forms of utilisation

As expected, under the third column the most common way that findings from these 62 studies were utilised was via peer-reviewed journal papers. Taking the peer-reviewed journal article as a marker of scientific quality, we found that most (n=11) of the above examples had their work published in this form, alongside the usual book chapters, conference papers or performances.

Evaluation

Of these 11, we 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. The results of this are placed under our final column entitled 'evaluation'.

Just three groups of studies went beyond what we called 'author self-reflection'. The next section contrasts these three groups of studies in terms of empirical qualitative data, publication in peer-reviewed journals, communication using non-traditional modes of dissemination and their evaluation – these are our key exemplars (Gray 2000; Gray 2003; Gray, Fitch et al. 2000, Gray et al. 2003; Gray & Sinding 2002; Gray, Sinding et al. 2000; Mienczakowski 1995, 1996, 1997, 2003; Morgan et al. 1993; Rolfe et al. 1995; Rozmovits & Ziebland 2004; Sillence et al. 2004).

Key Exemplars

In this section, we contrast the three groups of studies that went beyond author self-reflection in terms of empirical qualitative data, publication in peer-reviewed journals, the communication of findings using non-traditional modes of dissemination and their subsequent evaluation. 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.

Key Exemplar 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 countless 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.

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 this sample 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 is included with the book *Standing Ovation* (Gray & Sinding 2002).

'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 were 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.

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 a new level of awareness and understanding resulting 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).

As such, Gray references Jim Mienczakowski and the following two ethnodramas, *Syncing Out Loud* and *Busting.*

Key Exemplar 2

'Syncing Out Loud'

Both of the above 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).

Syncing Out Loud: A Journey into Illness 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).

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 was 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 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).

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 de-briefing 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).

This pilot project reworked and fictionalised informant experiences and then sought validation of them. However, the second project, *Busting*, adapted verbatim narrative into the form of 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).

'Busting'

Busting: The Challenge of a Drought Spirit 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 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).

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.

Key Exemplar 3

DIPEx

DIPEx, the Database of Personal Experiences of Health and Disease, 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 et al. 2000; Yaphe et al. 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 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).

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 that patients telling their story, analogous to when people give blood, have a sense of altruism and solidarity with others (Herxheimer et al. 2000).

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 contact with these personal experiences and planned to revisit their general practitioners or family physicians.

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.

Discussion

All three exemplars 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 (Morse 2004). However, 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 approaches to the intended audience (Nutley et al. 2002; Walter et al. 2003).

In paying attention to the communicative concern of qualitative research findings, we are compelled to re-examine the meaning of and explore the edges of research (Eisner 1997; Rapport et al. 2005). For instance, are there distinctions between what is art and what is research? Where do we draw the line between fact and fiction in translating research findings? The modes of dissemination mentioned above are more closely associated with media and art genres. This raises complex questions around how to evaluate such work.

Using drama and the internet to disseminate qualitative research findings requires expertise, be it technological or theatrical. Indeed, almost all modes of non-traditional dissemination 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, those the research is about, actors and script writers.

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.

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 et al. 2001).

Ethical issues

Not all research may be suited to particular modes of presentation, for example exploring suicide or child abuse through drama. Although little has been written about the ethical considerations of non-traditional modes of dissemination, 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 et al. 2001 p.193)

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 non-traditional modes of dissemination.

Using and evaluating research

Of the 62 texts we looked at, many of the authors did go beyond using the most traditional of passive dissemination techniques, the peer-reviewed journal manuscript, to disseminate their work. A smaller subset of authors used an empirical foundation for dissemination and just a handful evaluated their 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 curriculum.

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.

Conclusion

This review is by no means exhaustive. Searching for qualitative literature is made difficult because of the terms databases use to describe such studies. Many of our studies were found prior to database searching. We chose to use sensitive search terms even though we knew this would produce many unwanted abstracts. What we provide in this report is a partial picture of how qualitative research findings have been disseminated, based on our existing knowledge of the field, contacts with experts and an analysis of database and website searches. Further work is required to ensure that other fields of enquiry have not been overlooked. To this effect we make a call to be furnished with further scholarly examples of where the dissemination and impact of qualitative research findings have made a difference to practice, policy and people. There is a need for empirical work on how research is actually used so that research dissemination and utilisation is treated as involving more than building models of best practice (Shaw et al. 2004). Mullen (2003) challenges us to:

> 'go beyond creating insightful texts about the human condition to moving ourselves and others to action, with the effect of improving lives' (p.177) – 'the ethic of engagement' (p.169).

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Bagley & Cancienne (2001) is reprinted in the above book. The re-presentation of 10 in-depth interviews and the academic paper on which they are based (on UK school choice policy and its impact on families whose children have special educational needs) in the form of performed words and movement (dance), was staged at a 1998 US AERA conference. CB performed the researcher and MBC the choreographed movement (dance) and words of the parents. Some of the academic audience gave feedback on this methodological exploration, and the performance has been reproduced in CD format (see book below).

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BARNES V, CLOUDER L, HUGHES C, PURKIS J & PRITCHARD J. (2000) *Dissemination as evidence? Deconstructing the processes of disseminating qualitative research.* Symposium presented at the Qualitative Evidence-Based Practice Conference, Coventry University 15-17 May.

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Aimed at researchers, the above article is largely based on Barnes et al.'s (2000) conference presentation. It comprises a collection of education, health and social care vignettes (literature review and design, interviewing, analytical framework, presenting findings and journal articles as dissemination) to illustrate how the everyday processes of qualitative research can be reconfigured as dissemination. Therefore, dissemination is understood in its broadest sense and as a process entwined with reflexivity, not just as an end-point or product in a linear research design. One of the three responses to the 'evidence-based' movement is noted as a greater consciousness of devices and strategies in disseminating research findings.

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A conference performance using un-choreographed dance and spoken words makes argument for the use of dance as a mode of research representation. From a hermeneutical stance, the words that animate the script are transparent, text, meaningful action and the narrative of dance. The intent of this work is to stimulate thinking. A subsequent video of this performance is available from the author. The article contains both the script and notes elucidating it.

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Brackenbury looks at the story of care in her own family, particularly with her mother who, after 40 years of caring for seven children, continues to care for her 96-year-old mother. A quilting bee (a group of women who get together each week to make quilts) was a place where her mother had built strong connections with other women sharing the same experience. Talks with her family are represented using the form of a patchwork quilt alongside audio-taped dialogue, journal entries and a picture slide show. These were displayed to encourage further quilting bees and the liberation of women carers who tell their own stories through tapestry.

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This short article is written for the Association of Perioperative Registered Nurses. Research knowledge is mainly disseminated in verbal or written forms. Decisions on which form to use are based on your knowledge of the intended audience.

CAMPBELL R, POUND P, POPE C, BRITTEN N, PILL R, MORGAN M & DONOVAN J. (2003) Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science and Medicine*, **56**, 671-684.

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CLEARY LM & PEACOCK T. (1997) Disseminating American Indian educational research through stories: A case against academic discourse. *Journal of American Indian Education*, **37** (1), 7-15.
Educational dropout and achievement for American Indians is a serious problem. The authors question whether previous research findings have found their way into classrooms. They use a series of three open-ended, in-depth phenomenological interviews with 60 purposively selected teachers of American Indian students to produce a book of stories (*Collected Wisdom*) – the authors' stories, teachers' stories and fictional case studies based on fact. Remaining true to 'grounded theory' methods, they avoided a rigorous review of the literature until after they had collected and analysed the interview data.

CLOUGH P. (1999) Crises of schooling and the 'crisis of representation': The story of Rob. *Qualitative Inquiry*, **5** (3), 428-448.

COLE AL & MCINTYRE M. (2004) Living and dying with dignity: The Alzheimer's Project [online]. Available from http://home.oise.utoronto.ca/~aresearch/projects.html [Accessed 1 December 2004].
Both authors work at the Centre for Arts-Based Research at the University of Toronto. Their research in the form of journal entries, personal writing, care giving notes, photographs, personal documents, structured conversations, and library and internet research, is based on living with and caring for their mothers, both of whom had Alzheimer's.

The represented data comprises several 3D, real life multimedia presentations with descriptive and interpretive text. They tell the story of a life cycle – from a mother looking after her child, to a child, now adult, looking after her mother. These were exhibited in a CBC studio entrance in 2002. As advocacy work, aimed at family members and health professionals, the authors are concerned with research relevance and accessibility and with provoking and facilitating discussion among care providers.

CROWE TV. (2003) Using focus groups to create culturally appropriate HIV material for the deaf community. *Qualitative Social Work*, **2** (3), 289-308.

This study shows the use of five focus groups with 31 deaf individuals (convenience sample) to understand what the HIV/AIDS communication needs are of this population: design, recommend and evaluate prevention materials. A prevention poster, brochure and condom card were produced and presented at a main event for 10,000 deaf people and at places deaf individuals frequent. Crowe concludes that consideration should be given to the unique linguistic and cultural needs of the deaf population.

DEMARRAIS K. (2004) Elegant communications: Sharing qualitative research with communities, colleagues and critics. *Qualitative Inquiry*, **10** (2), 281-297.

Based on analyses of US government educational policies and their bent toward 'scientifically based inquiry', deMarrais addresses what is quality in qualitative research, how do we communicate or convey our work to others in ways that evoke understanding in them, and what role do emotions play in qualitative research and evaluation? She uses three stories to illustrate answers to the above questions and calls for the use of elegant communications, be they written or verbal (dependent on who the recipients are), for the use of emotions to be given a central place within educational research – and to engage with policy makers.

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London: Health Development Agency. Available from www.hda.nhs.uk [Accessed 19 November 2004].

EISNER EW. (1997) The promises and perils of alternative forms of data representation. *Educational Researcher*, **26** (6), 4-11.
The concept of alternative forms of data representation is not about the reduction of what we have learned to text and numbers. Instead it is the transformation of experience from the personal to the public. Aiming at educational and social science researchers, Eisner addresses the strengths and weaknesses of alternative forms of data representation. We use stories, pictures, diagrams, maps, poetry, film, demonstration and theatre to represent data. There is a relationship between our conception of what the products of research look like and the way we go about doing research. Considering these issues forces us to reassess the meaning of research. The value of research is determined by different communities. A potential strength may reside in the use of multimedia (image, text and music) displays for representing data.

ELLIOTT H & POPAY J. (2000) How are policy makers using evidence? Models of research utilisation and local NHS policy making. *Journal of Epidemiology and Community Health*, **54**, 461-468.

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EMSLIE C, HUNT K & WATT G. (2001a) 'I'd rather go with a heart attack than drag on': Lay images of heart disease and the problems they present for primary and secondary prevention. *Coronary Health Care*, **5**, 25-32.
See Emslie et al. (2001b).

EMSLIE C, HUNT K & WATT G. (2001b) Invisible women? The importance of gender in lay beliefs about heart problems. *Sociology of Illness and Health*, **23**, 203-233.
Few qualitative studies explore lay beliefs about heart problems in the general population. Hunt et al. (2001a, 2001b) and Emslie et al. (2001a) detail findings from the same qualitative study looking at lay beliefs about heart trouble with individuals living in West Scotland on the basis that health promotion initiatives are more likely to be successful if they work with (and not against) popular culture. In-depth interviews with 61 men and women, purposively selected from the findings of a previous Medical Research Council funded cross-sectional survey of cardio-respiratory disease, were completed after pre-pilot and pilot studies. Emerging hypotheses were fed back to respondents in later interviews. Although

the papers do not mention data transformation, one outcome for this study was the production in March 2001 of a four-page A4 health promotion brochure, published jointly by the Greater Glasgow Health Board and University of Glasgow.

ERVIN NE & COWELL JM. (2004) Integrating research into teaching public health nursing. *Public Health Nursing,* **21** (2), 183-190.

ESTABROOKS CA. (2001) Research utilization and qualitative research. In: JM Morse, JM Swanson & AJ Kuzel (eds.), *The Nature of Qualitative Evidence*. Thousand Oaks: Sage, pp275-298.

FARKAS M, JETTE AM, TENNSTEDT S, HALEY SM & QUINN V. (2003) Knowledge dissemination and utilization in gerontology: an organizing framework. *Gerontologist*, **43** (Special issue 1), 47-56.

FINFGELD DL. (2003) Metasynthesis: The state of the art – so far. *Qualitative Health Research*, **13** (7), 893-904.
Results from qualitative research continue to be obscure and have little impact on clinical practice, research or healthcare policy. A metasynthesis uses rigorous qualitative methods to examine and interpret findings from a number of qualitative studies. The aim of metasynthesis is to produce more substantive findings than those resulting from individual investigations. Three main foci of metasynthesis are described – theory building, theory explication and description. At least 17 metasyntheses have been conducted since 1994 on topics such as caring, diabetes, chronic illness and domestic violence. No clear guidelines exist for metasyntheses – contested issues include study focus, data sampling, triangulation and use of research teams, supporting evidence and audit trails. Finfgeld believes that the ability of metasyntheses to improve clinical practice, research and health care policies is the ultimate evaluative criterion.

FINLEY S. (2003) Arts-based inquiry in QI: Seven years from crisis to guerrilla warfare. *Qualitative Inquiry*, **9** (2), 281-296.

FOSKETT J, ROBERTS A, MATTHEWS R, MACMIN L, CRACKNELL P & NICHOLLS V. (2004) From research to practice: The first tentative steps. *Mental Health, Religion and Culture*, **7** (1), 41-58.

GERGEN M. (2003) Review note: Ross Gray & Christina Sinding (2002). Standing Ovation. Performing Social Science Research about Cancer [8 paragraphs]. *Forum Qualittive Sozialforschung/Forum: Qualitative Social Research* [online journal], **4** (3), Art. 12. Available from www.qualitative-

research.net.fqs-text/3-03/3-03review-gergen-e.htm [Accessed 15 December 2004].

GIBSON BE & MARTIN DK. (2003) Qualitative research and evidence-based physiotherapy practice. *Physiotherapy*, **89** (6), 350-358.

GILBERT K (ed.). (2001) *The Emotional Nature of Qualitative Research*. Boca Raton: CRC Press LLC.

GILGUN JF & ABRAMS LS. (2002) The nature and usefulness of qualitative social work research. *Qualitative Social Work*, **1** (1), 39-55.

GLESNE C. (1997) That rare feeling: re-presenting research through poetic transcription. *Qualitative Inquiry*, **3** (2), 202-221.
The author presents six poetic transcriptions (poem-like compositions from the words of interviewees) based on 10 hours' worth of interviews on the life of an 86-year old Puerto Rican professorial researcher and educator. After coding and sorting the data into major themes, Glesne re-reads the data under each theme and using the interviewees' words, portrays the essence of her understanding in poetic transcription. This type of experimental writing along with research-based theatre, short stories, dance or ethno-photography is considered to blur the accepted boundaries between art and science.

GODFREY R. (2004) Meta-analysis and qualitative data: Insights from the history of probability. *Building Research Capacity*, **7**, 9-11. Available from www.cardiff.ac.uk/socsi/capacity/Journal.html [Accessed 18 January 2005].

GRAY M. (2002) Art, irony and ambiguity. *Qualitative Social Work*, **1** (4), 413-33.

GRAY RE. (1998) Four perspectives on unconventional therapies. *Health*, **2** (1), 55-74.

GRAY RE. (2000) Graduate school never prepared me for this: Reflections on the challenges of research-based theatre. *Reflective Practice*, **1** (3), 377-390.
This paper describes and discusses reflections on a research-based theatre presentation (*Handle with Care?* Women living with metastatic breast cancer) based on interviews with the author, diary reflections and the experience of presenting qualitative data through drama. Now, the way Gray thinks about himself as a researcher has shifted to researcher as beginner, actor, observer, two-bit hustler, worrier, as one who suffers,

companion, agent of social transformation, and conveyor of hope. As at 2000 they had made close to 200 presentations.

GRAY RE. (2003a) Performing on and off the stage: The place(s) of performance in arts-based approaches to qualitative inquiry. *Qualitative Inquiry*, **9** (2), 254-267.
The research-based theatre performance *No Big Deal?* is a script based on longitudinal interviews with men with prostate cancer and their spouses. *No Big Deal?* performances led to a radio interview – the transcript is reproduced in this article. This media interview is reflected upon and treated as a semi-formal performance in itself.

GRAY, RE. (2003b) *Prostate Tales. Men's Experiences With Prostate Cancer.* Harriman, TN: Men's Studies Press.

GRAY R. (2004) No longer a man: Using ethnographic fiction to represent life history research. *Auto/Biography*, **12**, 44-61.
Gray provides the rationale for the use of ethnographic fiction in representing research findings in an evocative manner. This mode allows the reader to be immersed into the life situations of others. The story is told of an anonymous biologist with advanced prostate cancer and Gray, a social scientist, based on about 14 hours' of transcribed interviews. The style and order of the words, phrases and sentences from the transcripts are altered to give clarity and readability. The biologist provided extensive input on multiple drafts leading up to publication.

GRAY R, FITCH MI, LABRECQUE M, GREENBERG M. (2003) Reactions of health professionals to a research-based theatre production. *Journal of Cancer Education*, **18** (4), 223-229.
Twenty-six self-selecting health professionals (11 physicians, 7 nurses, 5 support staff and 3 radiation therapists) responded to an email call to participate in longitudinal interviews about their reactions to the play, *No Big Deal?*. *No Big Deal?* is a play based on longitudinal (n=3) interviews with 34 men and their spouses aimed at increasing awareness of health professionals, men and their families on issues related to prostate cancer. It was performed over 70 times at conferences, cancer treatment centres, community gatherings and workplace settings – a videotape is also available. A team of researchers coded and managed the health professional interview data using NUD.ist. Consistent comments across second and third interviews about the accuracy of the play provide validation of original study findings. Many reflected on a new type or level of awareness resulting from the play. All professionals commented on the actual and potential usefulness of drama based on research. Future research should consider how and in what context dramatic and narrative representation can be most effectively used.

GRAY RE, FITCH M, PHILLIPS C, LABRECQUE M, FERGUS K. (2000) Managing the impact of illness: the experiences of men with prostate cancer and their spouses. *Journal of Health Psychology,* **5**, 531-548.

GRAY R & SINDING C. (2002) *Standing Ovation: Performing Social Science Research About Cancer*. Walnut Creek: AltaMira Press.
This book covers in more detail the process of performing *Handle with Care?*.

GRAY R, SINDING C, IVONOFFSKI V, FITCH M, HAMPSON A & GREENBERG M. (2000) The use of research-based theatre in a project related to metastatic breast cancer. *Health Expectations*, **3**, 137-144.
Drama that emphasises research is topical. *Handle with Care?*, a research-based play, is based on data from a focus group study conducted about the information needs of women with metastatic breast cancer and an interview study with medical oncologists treating breast cancer patients. Over a period of at least six months, a group including researchers, actors from an Ontario university and women with breast cancer developed a draft script based on the above data and their experience. Feedback from a trial presentation to health professionals and breast cancer patients caused further changes. Audiences from subsequent performances to health professionals and volunteers working in a healthcare context (40%-50% response) and the general public (including patients with cancer, family members or friends – 60%-70% response) were asked to complete questionnaires (n=507). The general public (n=258) enjoyed seeing the drama (100%), agreed that the play made the subject seem more true to life (99%), and expressed a desire to see more dramatic productions about living with cancer. Health professional (n=249) audiences agreed or strongly agreed that the use of research transcripts to create drama increased its validity substantially. Issues presented were relevant to (95%) and useful for (93%) thinking about their clinical practice.

GREENWOOD D & LEVIN M. (1998) *Introduction to Action Research*. London: Sage Publications.

HAGELL A & SPENCER L. (2004) An evaluation of an innovative audio-tape method for keeping social care staff up to date with the latest research findings. *Child and Family Social Work*, **9** (2), 187-196.
Few studies have investigated how social care staff use and rate different sources of information. This small, exploratory, mainly qualitative pilot study assessed (with short questionnaires, focus groups and telephone interviews) how purposively chosen front line social workers and line managers (n=29) in four social service departments used one of six

audio-tapes displaying research messages. The aims of listening to the tape (once and in their car) were to help staff increase the time they gave to keeping up with research and improve understanding of it, thereby promoting better outcomes for children and families. Staff, often driven in their learning by the specific demands of their roles, declared a preference for interpersonal, informal and conversational learning materials.

HALIFAX ND, GRAY R, JADAD AR. (2004) Self-portraits of illness: The gift of the gaze. *Canadian Medical Association Journal*, **171** (7), 764-765.
A 78-year-old woman with colorectal cancer, who has since passed away, consented to the wide dissemination of a number of photographs in the hope of helping others to conquer feelings of being alone with the same disease. The context and meaning of these portraits is explained via verbatim quotes from talks with this woman and researcher narrative.

HARRISON S, DOWSWELL G, WRIGHT J & RUSSELL I. (2003) General practitioners' uptake of clinical practice guidelines: A qualitative study. *Journal of Health Services Research and Policy*, **8** (3), 149-153.

HERXHEIMER A, MCPHERSON A, MILLER R, SHEPPERD S, YAPHE J & ZIEBLAND S. (2000) Database of patients' experiences (DIPEx): A multimedia approach to sharing experiences and information. *Lancet*, **355**, 1540-1543.
The quality of 70% of health information on the internet is a problem. DIPEx is a Database of Personal Experiences of Health and Illness launched in July 2001 (www.DIPEx.org). Its aim is to cover and describe most of the 3,000 medical subject headings from a patient's point of view; to provide a resource for patients, carers and their families and the health professionals who look after them; and to promote a more balanced encounter (Yaphe et al. 2000) between patient and health professionals. By extension, a patient-centred perspective is a potential resource to learners and their educators, managers and those who commission health and social care services, policy makers, researchers and information technologists. Each module on DIPEx is based on the systematic collection (maximum variation sampling) and analysis of semi-structured qualitative interviews with people about their illness. The website combines audio, video and written collections of clips from the interviews covering all aspects of their illness and care. These are linked to frequently asked questions, reliable medical information, support groups and other useful resources. Academic papers have and are being written (for example, see Sillence et al. 2004, Yaphe et al. 2000, Ziebland 2004) to communicate findings to all who communicate with patients.

HERXHEIMER A & ZIEBLAND S. (2003) DIPEx: Fresh insights for medical practice. *Journal of the Royal Society of Medicine*, **96** (5), 209-210.

This editorial article contains four messages emerging from DIPEx: when people face a new diagnosis or dilemma they do not know how to find the information they need; doctors find some aspects of disease uncomfortable to talk about with patients; positive accounts of the NHS are reassuring; patients telling their story, analogous to when they give blood, receive a sense of altruism and solidarity.

HILLS MD. (2001) Using co-operative inquiry to transform evaluation of nursing students' clinical practice. In: H Bradbury & P Reason (eds.), *The Handbook of Action Research*. London: Sage, pp340-347.

HUNT K, EMSLIE C & WATT G. (2001) Lay constructions of a family history of heart disease: Potential for misunderstandings in the clinical encounter? *Lancet*, **357**, 1168-1171.

See comments on Emslie et al. (2001a, 2001b).

HURST K. (2002) Building a research conscious workforce. *Journal of Health Organization and Management*, **17** (5), 373-384.

JONES K. (2004) Mission drift in qualitative research, or moving toward a systematic review of qualitative studies, moving back to a more systematic narrative review. *The Qualitative Report*, **9** (1), 95-112. Available from www.nova.edu.ssss/QR/QR9-1/jones.pdf [accessed 12 January 2005].

KAJERMO KN, NORDSTROM G, KRUSEBRANT A & LUTZEN K. (2001) Nurses' experiences of research utilisation within the framework of an educational programme. *Journal of Clinical Nursing*, **10** (5), 671-681.

KOHLER CL, DOLCE JJ, MANZELLA BA, HIGGINS D, BROOKS CM, RICHARDS JM Jr & BAILEY WC. (1993) Use of focus group methodology to develop an asthma self-management program useful for community-based medical practices. *Health Education Quarterly*, **20** (3), 421-429.

KUSHNER S. (2004) Government regulation of qualitative evaluation. *Building Research Capacity*, **8**, 5-8. Available from www.cardiff.ac.uk/socsi/capacity/Journal.html [Accessed 18 January 2005].

LEVIN B. (2003) Increasing the impact and value of research in education. *Building Research Capacity*, **6**, 1-3. Available from

www.cardiff.ac.uk/socsi/capacity/Journal.html [Accessed 18 January 2005].

LINCOLN YS. (2004) Performing 9/11: teaching in a terrorized world. *Qualitative Inquiry*, **10** (1), 140-159.

LLOYD-JONES G & HAK T. (2004) Self-directed learning and student pragmatism. *Advances in Health Sciences Education*, **9**, 61-73.

MANN E & REDWOOD S. (2000) Improving pain management: Breaking down the invisible barrier. *British Journal of Nursing*, **9** (19), 2067-2072.

MCCORMACK J, LOEWEN P, JEWESSON P. (2005) Dissemination of results needs to be tracked as well as the funding? [Letter] *British Medical Journal*, **331**, 456.

MCNIFF J, LOMAX P, WHITEHEAD J. (1996) *You and Your Action Research Project.* London: Routledge Falmer.

MEYER J. (2000) Using qualitative methods in health-related action research. *British Medical Journal*, **320**, 178-181.

MIENCZAKOWSKI J. (1995) The theatre of ethnography: The reconstruction of ethnography into theatre with emancipatory potential. *Qualitative Inquiry*, **1** (3), 360-375.
This article is reprinted as Mienczakowski (2003) and describes two ethnodramas: *Syncing Out Loud: A journey into illness* and *Busting: The challenge of the drought spirit*. The former was a fictionalised dramatic pilot study based on research, health consumer experiences of psychosis (schizophrenia) and attitudes toward treatment regimens. Each stage of data collection, script writing and performance was subject to informant validation. This pilot project informed *Busting*, an ethnodrama with the aim of giving voice to health consumers and workers on the realities of life in an urban drug and alcohol withdrawal (detox) unit – in particular of the experience of acute alcohol withdrawal. Data gathered by ethnographers, unit staff and final year nursing students via participant observation and interactionist interviews were collated over a four-month period – all, including informants and actors, were involved in validational processes for script development and performance. *Syncing Out Loud* fictionalised informant experiences whereas informants for *Busting* demanded the adaptation of verbatim narrative into script. Repeated (recorded) discussion of meanings after performances sought to create a consensus of informed opinion for both informants and audiences. Performances to health consumers, students, educators, professionals,

service providers, general public, high school students and community drug and alcohol representatives took place in clinical, university and conference settings. There was wide press and media coverage provoking a response from health service providers on the issues raised. For both plays, counsellors, psychiatric nurses and other support agency representatives were made available to performance audiences, along with copies of the script. Script versions have also been used as teaching materials for nursing and performing arts students.

MIENCZAKOWSKI J. (1996) An ethnographic act. The construction of consensual theatre. In: C Ellis & AP Bochner (eds.), *Composing Ethnography: Alternative Forms of Qualitative Writing*. Walnut Creek: AltaMira Press, pp244-264.

This article, similar to Mienczakowski's other work (1995, 1997), focuses on the development of two ethnographically based plays: *Syncing Out Loud: A journey into illness* and *Busting: The challenge of the drought spirit*.

MIENCZAKOWSKI J. (1997) Theatre of change. *Research in Drama Education*, **2** (2), 159-172.

This article, similar to Mienczakowski's other work (1995; 1996), focuses on the development and impact of two ethnographically based plays: *Syncing Out Loud: A journey into illness* and *Busting: The challenge of the drought spirit*. This type of research activity has multiple applications and implications for student performance training, research training, nursing education and health education.

MIENCZAKOWSKI J. (2001) Ethnodrama: performed research – limitations and potential. In: P Atkinson, A Coffey, S Delamont, J Lofland & L Lofland (eds.), *Handbook of Ethnographic Research*. London: Sage, pp468-476.

Ethnodramas construct script and performance using consensus methods, with informants controlling both text and representation. They seek to weld textual, academic presentation and performance values in its investigation of human understanding – into a form of public voice ethnography that has emancipatory and educational potential. Ethnodrama does not appear suited to issues that put audiences at risk, for instance, suicide.

MIENCZAKOWSKI J. (2003) The theatre of ethnography: The reconstruction of ethnography theatre with emancipatory potential. In: N Denzin & Y Lincoln (eds.), *Turning Points in Qualitative Research: Tying Knots in a Handkerchief*. Thousand Oaks: AltaMira Press, pp415-432.

This chapter was originally published as an article in 1995. A synopsis of this article is placed under Mienczakowski (1995).

MIENCZAKOWSKI J & MORGAN S. (2001) Ethnodrama: Constructing participatory experiential and compelling action research through performance. In: H Bradbury & P Reason (eds.), *The Handbook of Action Research*. London: Sage, pp219-227.

This article is highly similar to that of Mienczakowski (2001), yet written from an action research perspective. The ethical considerations for performed research informants and audiences are not well recognised or understood.

MIENCZAKOWSKI J, MORGAN S & SMITH L. (2001) An act of subversion: Night workers on the fringe of dawn – from bow-wave to deluge. In: K Gilbert (ed.), *The Emotional Nature of Qualitative Research.* Boca Raton: CRC Press LLC, pp179-194.

MIENCZAKOWSKI J, SMITH L & MORGAN S. (2002) Seeing words – hearing feelings: Ethnodrama and the performance of data. In: C Bagley & MB Cancienne (eds.), *Dancing the Data*. New York: Peter Lang, pp34-52.

Ethnodrama seeks to represent, demonstrate and remain true to the informants who contribute (qualitative) data on their lived experience – often marginalised health-care recipients and their carers. So, individual (actor) performance and theatrical style are secondary to the accuracy and credibility of script and performance. Scripts are usually constructed under the control of health informants, health agency representatives and health professionals. Performances may be cathartic for audiences. The audience is also part of script and performance validation. Minimising potential risks to vulnerable audiences such as school children is essential.

MORGAN S, MIENCZAKOWSKI J & SMITH L. (2001) Extreme dilemmas in performance ethnography: Unleashed emotionality of performance in critical areas of suicide, abuse and madness. In: K Gilbert (ed.), *The Emotional Nature of Qualitative Research*. Boca Raton: CRC Press LLC, pp163-178.

Ethnodramas may unleash unanticipated emotional responses from audiences of health informants, health agency representative and health professionals, government and business representatives and the general public. The problem is that there is little evidence on the impact of such dramas. A valid and accurate performance of pathogen experience, even those using validatory procedures, may not necessarily be an ethical one.

MORGAN S, ROLFE A & MIENCZAKOWSKI J. (1993) It's funny, I've never heard voices like that before. Reporting into research performance work in schizophrenia. *The Australian Journal of Mental Health Nursing*, **2** (6), 266-272.

The play *Syncing Out Loud* was performed for clients, relatives and staff at a large psychiatric hospital. Each scene portrays a different perspective of the schizophrenic experience set within a fictitious psychiatric care conference. The play promotes awareness of aspects of the schizophrenic experience to mental health consumers and providers. The impetus for the project came from the desire to explicate and reflect the nature of power relations inherent in psychiatry, and to facilitate mental health nursing and drama course objectives in a university setting. Feedback on the project was gained from consumers, written responses and structured small group work.

MORSE JM (2000) The downside of dissemination. *Qualitative Health Research*, **10** (3), 291-292.

MORSE JM. (2004) Alternative modes of representation: There are no shortcuts. *Qualitative Health Research*, **14** (7), 887-888.

MORSE JM, SWANSON JM & KUZEL AJ. (eds.) (2001) *The Nature of Qualitative Evidence*. Thousand Oaks: Sage.

MOSELEY D, HIGGINS S, BRAMALD R, HARDMAN F, MILLER J, MROZ M, HARRISON T, NEWTON D, THOMPSON I, WILLIAMSON J, HALLIGAN J, BRAMALD S, NEWTON L, TYMMS P, HENDERSON B & STOUT J. (1999) *Ways Forward with ICT: Effective pedagogy using information and communications technology for literacy and numeracy in primary schools*. Newcastle: University of Newcastle. Available from the Education Line Database based at the University of Leeds www.leeds.ac.uk/educol/documents/00001369.htm [Accessed 18 January 2005].

MULLEN CA. (2003) Guest editor's introduction: 'A self-fashioned gallery of aesthetic practice'. *Qualitative Inquiry*, **9** (2), 165-181.

MULLEN EJ, SHLONSKY A, BLEDSOE SE & BELLAMY JL. (2005) From concept to implementation: Challenges facing evidence-based social work. *Evidence and Policy: A Journal of Research, Debate and Practice*, **1** (1), 61-84.

MURPHY E & DINGWALL R. (2004) A response to 'Quality in qualitative evaluation: a framework for assessing research evidence'. *Building Research Capacity*, **8**, 3-4. Available from www.cardiff.ac.uk/socsi/capacity/Journal.html [Accessed 18 January 2005].

MURPHY E, DINGWALL R, GREATBATCH D, PARKER S, WATSON P. (1998) Qualitative research methods in health technology assessment: A review of the literature. *Health Technology Assessment*, **2** (16).

NICHOLLS L. (2005) *What makes a good midwife?* Presentation given at the Improving Maternity Services Conference, London, 27 January 2005.

NUTLEY S, PERCY-SMITH J, SOLESBURY W. (2003) Models of research impact: A cross sector review of literature and practice. London: Learning and Skills Research Centre.

NUTLEY S, WALTER I & DAVIES H. (2002) From knowing to doing: A framework for understanding the evidence into practice agenda. St Andrews: University of St. Andrews. Available from www.st-andrews.ac.uk/%7Eruru/publications.htm [Accessed 19 January 2005].

OIKARINEN-JABAI H. (2003) Toward performative research: Embodied listening to the self/other. *Qualitative Inquiry*, **9** (4), 569-579.

OWEN J & COOKE J. (2004) Developing research capacity and collaboration in primary care and social care. *Qualitative Social Work*, **3** (4), 389-410.

PARKER J, PENHALE B, BRADLEY G & MANTHORPE J. (1998). The EQUAL Project: Action research for the development of practice in dementia care. *Issues in Social Work Education*, **18** (2), 89-96.

PATERSON BL, THORNE SE, CANAM C & JILLINGS C. (2001) *Meta-Study of Qualitative Health Research*. Thousand Oaks: Sage.

PAWSON R, BOAZ A, GRAYSON L, LONG A & BARNES C. (2003) *Knowledge Review 3. Types and Quality of Knowledge in Social Care*. London: Social Care Institute for Excellence.

PHILLIPS A. (2004) Care, values and an uncaring media. *Social Policy and Society*, **3** (4), 439-446.

PIFER DA. (1999) Small town race: A performance text. *Qualitative Inquiry*, **5** (4), 541-562.
The performance text in this article comprises four scenes aiming to raise race issues in rural communities for academic and student audiences. The text has been constructed from interviews with two white male 'problem' juniors attending rural high school, data from eight weeks of student and teacher observation, newspaper cuttings and autobiographical reflections. Pifer intends this text to be performed.

POPAY J & ROEN K. (2003) Synthesis of evidence from research using diverse study designs: A review of selected methodological work. *Health Care Reports*, **1** (1), Adelaide: Joanna Briggs Institute.

POTOCNIK J. (2005) *Let's Make Science the Next Headline*. Keynote speech. Communicating European Research Conference, Brussels, 14 November.

RAPPORT F, WAINWRIGHT P & ELWYN G. (2005) 'Of the edgelands': Broadening the scope of qualitative methodology. *Medical Humanities*, **31** (1), 37-42.

REASON P & HERON J. (1999) A Lay Person's Guide to Co-operative Inquiry. Available from www.bath.ac.uk/carpp/layguide.htm [Accessed 18 November 2003].

RICHARDSON L. (1992) The consequences of poetic representation. Writing the other, rewriting the self. In: C Ellis & M Flaherty (eds.), *Investigating Subjectivity. Research on Lived Experience*. Thousand Oaks: Sage, pp125-137.
Richardson fashions the text of a 36-page interview with an unmarried mother, Louisa May, into a three-page poem using only Louisa May's words. In this article, Richardson focuses on the unanticipated consequences to herself of this construction in terms of writing, speaking, seeing and feeling. The poem has been presented to diverse audiences such as sociologists, poets, feminists, lay listeners and so on – each reacted in different ways.

RITCHIE J & LEWIS J. (eds.) (2003) *Qualitative Research Practice*. London: Sage.

ROGERS D, FRELLICK P & BABINSKI L. (2002) Staging a study: Performing the personal and professional struggles of beginning teachers. In: C Bagley & MB Cancienne (eds.), *Dancing the Data*. New York: Peter Lang, pp53-69.
The authors aimed to help new teachers (n=100) in North Carolina understand more about their first year experiences through bi-weekly, problem-solving, discussion-based support groups (n=19) (1995-2000). Based on group transcripts and exit interviews (n=49), an original research report was completed. This was found to be empty and lifeless. The authors experimented with the data in the form of a play, to feedback the voices of teachers to both teachers and administrators in a more accessible way. A copy of the script is contained in this chapter in the hope that it will be performed by others to help those new to teaching.

ROLFE A, MIENCZAKOWSKI J & MORGAN S. (1995) A dramatic experience in mental health nursing education. *Nurse Education Today*, **15** (3), 224-227.
The play *Syncing Out Loud* is set in a fictitious conference where delegates present papers defining mental health and community issues surrounding schizophrenia. At the same time, the play follows the experiences of a newly diagnosed sufferer. Students were involved in performance, post-performance discussion, debriefing sessions, personal journal writing and the submission of a final reflection paper. The experience of these students is examined in the paper. The play was performed at a university and psychiatric hospital to raise consciousness in the community about schizophrenia, as well as to develop an alternative approach to nursing education.

ROZMOVITS L & ZIEBLAND S. (2004) What do patients with prostate or breast cancer want from an internet site? A qualitative study of information needs. *Patient Education and Counseling*, **53**, 57-64.
Little is known about how people with serious disease use the internet as a source of health information to meet their information needs. Purposively selected participants (n=28) were recruited from breast and prostate cancer support groups to four focus groups. From these, eight individual interviews were conducted (two from each focus group) to ask about specific cancer information needs. Interviewees were then shown the DIPEx module and asked whether it would have fulfilled their unmet information needs. A short semi-structured interview solicited their views on the website. Of the 16 information needs described in both focus groups and interviews, nine were covered by the website – seven were at the planning stage. The focus on the experiences of other patients appears particularly valued.

RYCROFT-MALONE J, HARVEY G, SEERS K, KITSON A, MCCORMACK B & TITCHEN A. (2004) An exploration of the factors that influence the implementation of evidence into practice. *Journal of Clinical Nursing*, **13**, 913-924.

SALDANA J. (2003) Dramatizing data: A primer. *Qualitative Inquiry*, **9** (2), 218-236.

SANDELOWSKI M. (1998) Writing a good read: Strategies for re-presenting qualitative data. *Research in Nursing and Health*, **21** (4), 375-382.

SANDELOWSKI M. (2004) Using qualitative research. *Qualitative Health Research*, **14** (10), 1366-1386.

SAVA I & NUUTINEN K. (2003) At the meeting place of word and picture: Between art and inquiry. *Qualitative Inquiry*, **9** (4), 515-534.

SCHEYETT A. (2004) The research to teaching initiative: Infusing faculty research into the NSW curriculum. *Social Work Education*, **23** (3), 341-346.

SELLS D, TOPOR A & DAVIDSON L. (2004) Generating coherence out of chaos: Examples of the utility of empathic bridges in phenomenological research. *Journal of Phenomenological Psychology*, **35** (2), 253-271.
Two transcribed interviews exploring factors impacting recovery from serious mental illness were given to five experienced qualitative researchers for them to write, independently, a one-page narrative summary in the first person. One researcher then wrote a narrative summary based on themes highlighted across all previous summaries. Both summaries were subject to further refining before publication. Traditionally, narratives are written in the third person. The process offers an opportunity for researchers to build empathic bridges to informant experience.

SHAW I. (2004) *Qualitative Methods and Evaluation.* A paper given at Massey University, 4 March 2004.

SHAW I, ARKSEY H, MULLENDER A. (2004) *ESRC (Economic and Social Research Council) Research, Social Work and Social Care.* Bristol: SCIE/Policy Press.
This consultation exercise took place over an eight-week period late in 2003. Analysis of ESRC documentation identified two research programmes with social work relevance. All principal applicants (n=53) of projects funded under these programmes were sent an 11 item email questionnaire to find out their perceptions of being funded by the ESRC and the actual and potential coverage of social work and social care within individual projects; 16 responded. Later in the study, a mid-way consultation workshop was attended by eight researchers, and two further face-to-face interviews with two senior ESRC staff were completed. 'There is a need for empirical work on how research is, in fact, used, so that research utilisation is treated as involving more than model building of best practice' (p.4). There is 'a major agenda for how utilisation and transfer bridges are made' (p.12). Talk around how project findings could influence policy and practitioners emphasised passive rather than active utilisation models. There was far greater emphasis on the projects' impact on research methodology. 'Respondents were asked about the dissemination and utilisation of project findings. There was a general sense that linkages of this kind are typically seen as a function

lying beyond the project' (p.13). One suggestion is to resource research dissemination properly. Shaw et al. recommend that 'it should be a requirement of all ESRC applications to provide evidence that active utilisation strategies have been considered and appropriately taken into account in the costings' (p.16).

SIKES P. (2005) Storying schools: Issues around attempts to create a sense of feel and place in narrative research writing. *Qualitative Research*, **5** (1), 79-94.

SILLENCE E, BRIGGS P & HERXHEIMER A. (2004) Personal experiences matter: What patients think about hypertension information online. *He@lth Information on the Internet*, **42**, 3-5. Available from www.hioti.org [Accessed 12 January 2004].
Thirteen people with hypertension were recruited via a local newspaper advert to search the internet for four, two-hour sessions at Northumbria University. Participants spent the first hour searching the internet (logging their thoughts and opinions of websites) and the second taking part in a wider discussion about the role of the internet in health advice. They found the DIPEx site well laid out and easy to search, commending the audio and video links, and question and answer sections. DIPEx presented many genuine personal experiences, i.e. information participants could not find on other sites (see Herxheimer et al. 2000 for a fuller exploration of DIPEx.)

SLOPER P, MUKHERJEE S, BERESFORD B, LIGHTFOOT J & NORRIS P. (1999) *Real Change Not Rhetoric: Putting research into practice in multi-agency services.* Bristol: JRF/Policy Press.

SMITH P, MASTERSON A, BASFORD L, BODDY G, COSTELLO S, MARVELL G, REDDING M & WALLIS B. (2000) Action research: A suitable method for promoting change in nurse education. *Nurse Education Today*, **20**, 563-570.

SPARKES AC. (2002) *Telling Tales in Sport and Physical Activity: A Qualitative Journey.* Champaign: Human Kinetics.

SPARKES AC. (2003) Review Essay. Transforming qualitative data into art forms. *Qualitative Health Research*, **3** (3), 415-420.

SPENCER L, RITCHIE J, LEWIS J & DILLON L. (2004) Quality in qualitative evaluation: A framework for assessing research evidence. London: Government Chief Social Research's Office.

SPRY T. (2001) Performing autoethnography: An embodied methodological praxis. *Qualitative Inquiry*, **7** (6), 706-732.

SPUNT BS, DEYO RA, TAYLOR VM, LEEK KM, GOLDBERG HI & MULLEY AG. (1996) An interactive videodisc programme for low back pain patients. *Health Education Research*, **11** (4), 535-541.

SURI H. (1998) *A Critique of Contemporary Methods of Research Synthesis.* Melbourne: University of Melbourne. Available from www.aare.edu.au/98pap/sur98250.htm [Accessed 15 December 2004].

THORNE S. (2000) Off the shelves and into the streets. *Canadian Journal of Nursing Research*, **32** (3), 103-107.

TIERNEY WG. (2002) Get real: Representing reality. *International Journal of Qualitative Studies in Education*, **15** (4), 385-398.

TILLECZEK K, CHEU H, PONG R & BOYDELL K. (2004) *Research Goes to the Cinema: Rural Research Knowledge Translation and Documentary Film. Paper* presented at the 5th Canadian Rural Health Research Society Conference and 4th International Rural Nursing Congress, Sudbury, Ontario, Canada, 21-23 October.
This conference paper describes the transformation into a documentary film of 30 interviews with parents of children with mental health issues and 30 interviews with service providers. The documentary demonstrates the realities of the rural mental health 'system' from the point of view of family members. The paper includes issues such as ethics, the way social science and film methodologies differ, turning written material into visual narrative, reflexivity and editing.

TODRES L. (1998) The qualitative description of human experience: The aesthetic dimension. *Qualitative Health Research*, **8** (1), 121-127.

TODRES L. (1999) The bodily complexity of truth telling in qualitative research: Some implications of Gendlin's theory. *The Humanistic Psychologist*, **27** (3), 283-300.

TODRES L. (2000) Writing phenomenological-psychological descriptions: An illustration attempting to balance texture and structure. *Auto/Biography*, **8** (1&2), 41-48.

TODRES L. (2004) The meaning of understanding and the open body: Some implications for qualitative research. *Existential Analysis*, **15** (1), 38-54.

TODRES L & HOLLOWAY I. (2004) Descriptive phenomenology: Life-world as evidence. In: F. Rapport (ed.), *New Qualitative Methodologies in Health and Social Care Research*. London: Routledge, pp79-98.

TODRES L & MACDONALD K. (eds.) (2001) *Making it Better: Improving Health and Social Care Through Interprofessional Learning and Practice Development*. Bournemouth: Bournemouth University.

TORRANCE H. (2004) 'Quality in Qualitative Evaluation' – a (very) critical response. *Building Research Capacity*, **8**, 8-10. Available from www.cardiff.ac.uk/socsi/capacity/Journal.html [Accessed 18 January 2005].

TRAYNOR M. (1999) The problem of dissemination: Evidence and ideology. *Nursing Inquiry*, **6** (3), 187-197.

TROMAN G. (2001) Tales from the interface: Disseminating ethnography for policy making. In: G Walford (ed.), *Ethnography and Education Policy*. London: JAI, pp251-273.

VINGILIS E, HARTFORD K, SCHRECKER T, MITCHELL B, LENT B & BISHOP J. (2003) Integrating knowledge generation with knowledge diffusion and utilization. A case study analysis of the consortium for applied research and evaluation in mental health. *Canadian Journal of Public Health*, **94** (6), 468-471.

WALTER I, NUTLEY S & DAVIES H. (2003) *Research Impact: A Cross-Sector Review*. St Andrews: University of St. Andrews. Available from www.st-andrews.ac.uk/%7Eruru/publications.htm [Accessed 19 January 2005].

WALTER I, NUTLEY S, PERCY-SMITH J, MCNEISH D & FROST S. (2004) *Summary Knowledge Review 7. Improving the Use of Research in Social Care Practice.* London: Social Care Institute for Excellence.

WATERMAN H, TILLEN D, DICKSON E, De KONING K. (2001) Action research: A systematic review and guidance for assessment. *Health Technology Assessment* **5** (23).

WILLIS P. (2004) From 'The Things Themselves' to a 'Feeling of Understanding': Finding different voices in phenomenological research. *Indo-Pacific Journal of Phenomenology*, **4** (1), 1-13. Retrieved 4 August 2005, from www.ipjp.org/august2004/willis4e1.pdf.

YAPHE J, RIGGE M, HERXHEIMER A, MCPHERSON A, MILLER R, SHEPPERD S & ZIEBLAND S. (2000) The use of patients' stories by self-help groups: A survey of voluntary organizations in the UK on the register of the College of Health. *Health Expectations*, **3**, 176-181.

In May 1999, 2,458 groups and individuals on the College of Health register were sent a questionnaire to inform them about the DIPEx database and to find out in what ways self-help groups are collecting and using patients' stories. Content analysis of the 309 free text responses showed that the most common use of stories is for articles in a group newsletter (37%), broadcast media (15%) and booklets of members' illness experiences (12%).

ZIEBLAND S. (2004) The importance of being expert: The quest for cancer information on the internet. *Social Science and Medicine*, **59**, 1783-1793.

There is concern about the quality of health information on the internet. Few empirical studies examine how the internet is used by those who have serious illness. This paper tells the story of two participants of the DIPEx breast and prostate cancer modules – about how, when and why they use the internet within the context of their experience of cancer. The internet was used to gather information, support them and make sense of their cancer experience.

ZIEBLAND S, CHAPPLE A, DUMELOW C, EVANS J, PRINJHA S & ROZMOVITS L. (2004) How the internet affects patients' experiences of cancer: A qualitative study. *British Medical Journal*, **328**, 564-569.

This study uses the 175 interviews with cancer patients for DIPEx modules to explore their use of the internet. Little empirical work looks at how people with serious illness use internet information. The results show the many different ways the internet is used by people with serious illness at all stages of their illness and follow-up.

Appendix 1: Database Search Results

Databases	Academic Search Elite EBSCO	Australian Education Index 1976-Sept 2004	British Education Index 1976-Sept 2004	CINAHL via OVID 1982-2004	eLSC/Caredata	ERIC 1990-2004	LISA 1969-2004	MEDLINE via OVID 1966-2004	PsycINFO via OVID 1967-2004	SOSIG	Web of Knowledge 1981-2004
Search date	15/12/04	15/12/04	15/12/04	15/12/04	25/11/04	15/12/04	15/12/04	15/12/04	15/12/04	15/12/04	15/12/04
Search terms	'qualitative and disseminat*'	'qualitative and dissemination'	'qualitative and dissemination'	47 line search string	'dissemination of research'	'dissemination and qualitative'	'qualitative and dissemination'	29 line search string	32 line search string	'disseminat* and qualitative'	'qualitative and disseminat*'
Number of hits	75	16	7	196	126	69	41	219	112	9	224
References for review	6 (already had 3)	2	2	12 (already had 8)	8	1	2	8 (already had 4)	3 (already had 3)	1	6 (already had 3)
Remainder rejected as:											
Not dissemination	29	5	4	87		22	10	115	78		45
Qualitative research methods	9			18		5	8	13	6	1	14
Not qualitative research	14	9	1	33	32	33	11	45	15		15
Evaluation	4			13	17	7		4	1		18
Medical	3			10				25			84
Information articles	3				29		10		1	7	13
Evidence-based references	2			4	9			3	1		
Research methods in general	5			13	17			4	7		26
Review articles				6		1		2			
Policy					8						
Education					6						

Appendix 2: Table of Reviewed Studies

Key: NA = North American; UK = United Kingdom

Paper number	Empirical qualitative findings	Non-traditional mode(s) of dissemination	Other forms of utilisation	Evaluation
1-2 Barnes et al. (UK) (2000, 2003)			Conference paper and peer-reviewed journal article on the concept of dissemination.	
3 Sparkes (UK) (2003)			Review essay, in part, on 4-5.	
4-5 Bagley (UK) & Cancienne (NA) (2001, 2002)	Based on ten in-depth interviews on UK school choice policy with families whose children have special educational needs. Peer-reviewed.	Performed words and movement (dance).	Conference paper/performance, peer-reviewed journal paper and book chapter.	Author self-reflection.
6 Brackenbury (NA) (2004)	Based on audio-taped stories of care, journal entries and pictures from within the author's family.	Patchwork quilt of care stories.	Internet journal.	
7 Byrne (NA) (2001)			Short review article on disseminating and presenting qualitative findings.	
8 Cleary & Peacock (NA) (1997)	Based on longitudinal interviews with 60 teachers of American Indian students, plus a further 80 interviews with teachers of indigenous students around the world.	Story-telling.	Book and peer-reviewed journal article.	
9 Blumenfeld-Jones (NA) (1995)		Unchoreographed dance and spoken words as a means to make philosophical argument for the use of dance as a mode of research representation.	Conference performance and peer-reviewed journal papers.	
10 Cole & McIntyre (NA) (2004)	Based on the authors' diaries, personal documents, structured conversations, photographs and experience of living with and caring for their mothers, both of whom had Alzheimer's disease.	3D multi-media presentation.	Television studio entrance and newsletter.	
11 Crowe (NA) (2003)			Peer-reviewed journal paper on the use of focus groups to develop HIV prevention materials for the deaf and hard of hearing community.	
12 deMarrais (NA) (2004)			Peer-reviewed journal paper based on analyses of US government educational policies. She calls for elegant communication.	
13 Eisner (NA) (1997)			Peer-reviewed journal paper on the promises and pitfalls of alternative forms of data representation.	

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An annotated bibliographic review of non-traditional dissemination strategies

Paper number	Empirical qualitative findings	Non-traditional mode(s) of dissemination	Other forms of utilisation	Evaluation
14 Ellis & Bochner (NA) (1996)			Book of essays exploring autoethnography, sociopoetics and reflexive ethnography.	
15 Emslie et al. (UK) (2001a, 2001b), Hunt (UK) et al. (2001)	Based on in-depth interviews with 61 men and women on lay beliefs about heart trouble.	A4 health promotion brochure.	A4 health promotion brochure and three peer-reviewed journal papers.	
16 Ervin & Cowell (NA) (2004)			Peer-reviewed journal article describing an innovative approach to integrate research skills into public health nursing courses.	
17 Finfgeld (NA) (2003)			Peer-reviewed journal article on the current state of the meta-synthesis of qualitative work.	
18 Foskett et al. (UK) (2003)			Peer-reviewed article tracing the history of the Somerset spirituality project.	
19-23 Gray (NA) (2000, 2003, 2004), Gray et al. (2000, 2003)	Based on longitudinal interviews with men with prostate cancer and their spouses, a focus group study on the information needs of women with metastatic breast cancer, interviews with oncologists and 14 hours of transcribed interviews with a man with advanced prostate cancer.	Research-based theatre (text and performance), evocative writing and video.	Two books, five peer-reviewed journal papers, media interview and 270 live presentations at conferences, cancer treatment centres, community gatherings and workplace settings.	Author self-reflection, facilitated audience feedback and discussion immediately after performance and longitudinal telephone interviews with audience.
24 Glesne (NA) (1997)	Based on 10 hours of interviews over a one-week period with an 86-year-old Puerto-Rican researcher and educator (professor).	Poetic transcription.	Peer-reviewed journal paper.	
25-31 Rozmovits & Ziebland (UK) (2004), Sillence et al. (UK) (2004)	Based on focus group discussion, interviews and log of thoughts of opinions of DIPEx and other websites with 13 hypertensive adults.	Website display of interview clips of those with hypertension and breast and prostate cancer in audio, video and written form, and DVDs	Peer-reviewed journal papers (Ziebland et al. 2004, Ziebland 2004).	User evaluation (Rozmovits & Ziebland 2004, Sillence et al. 2004).
32 Hagell & Spencer (UK) (2004)		Audio tape.	Peer-reviewed journal paper on using an audio tape to feedback research messages.	Perceptions of social care staff.
33 Halifax (NA) (2004)		Photographs.	Peer-reviewed journal paper on a woman with colorectal cancer.	
34 Jones (UK) (2004)			Peer-reviewed internet journal review paper on the systematic review of qualitative research.	

Paper number	Empirical qualitative findings	Non-traditional mode(s) of dissemination	Other forms of utilisation	Evaluation
35 Levin (NA) (2003)			Internet journal paper on increasing the impact and value of research in education.	
36-45 Mienczakowski (Australia) (1995, 1996, 2003), Morgan et al. (1993), Rolfe et al. (1995)	Based on longitudinal data gathered by ethnographers, unit staff and nursing students via participant observation and interactionist interviews on alcoholic withdrawal and schizophrenia.	Ethnodramas (text and performance), audio and video.	Peer-reviewed journal papers, book chapters and live performances to the public, students, caregivers, health consumers, health professionals and educators in clinical and university settings. Widespread media coverage.	Author self-reflection, audience discussion (Mienczakowski 1995, 2003) and student feedback (Rolfe et al. 1995).
46 Morse (NA) (2000)			Editorial on the downside of dissemination.	
47 Morse (NA) (2004)			Editorial on alternative modes of representation.	
48 Morse et al. (NA) (2001)			Book endeavouring to answer the questions: how good is qualitative inquiry? What use is it?	
49 Mullen (NA) (2003)			Editorial review essay on creative forms of research representation.	
50 Parker et al. (UK) (1998)			Peer-reviewed journal paper on an action research project to select, recruit and train volunteers to run reminiscence groups with people with Alzheimer's.	
51 Pifer (NA) (1999)	Based on eight weeks' observation of student teacher interaction and two interviews with two white male students on the theme of race relations in a rural community.	Unperformed performance text.	Peer-reviewed journal paper.	
52 Richardson (NA) (1992)	Based on one interview with an unmarried mother.	Poetic text.	Book chapter and presentations to diverse audiences.	Author self-reflection and informal audience discussion.
53 Rogers et al. (NA) (2002)	Based on 19 transcribed discussion support groups to help first year teachers (n=100) understand more about their experiences; plus 49 exit interviews.	Unperformed play script.	Book chapter.	
54 Saldana (NA) (2003)			Peer-reviewed journal paper focusing on dramatising qualitative data.	
55 Sandelowski (NA) (1998)			Peer-reviewed journal paper on strategies for representing qualitative data.	

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Paper number	Empirical qualitative findings	Non-traditional mode(s) of dissemination	Other forms of utilisation	Evaluation
56 Sells et al. (NA/Sweden) (2004)	Based on two interviews exploring factors impacting recovery from severe mental illness.	Evocative writing (storytelling).	Peer-reviewed journal paper.	
57 Smith et al. (UK) (2000)	Based on action research to disseminate and implement findings from a study exploring the extent to which a philosophy of health had been integrated into nursing curricula.	Meetings and workshops to develop action plans.	Peer-reviewed journal paper and meetings and workshops to develop action plans.	
58 Sparkes (UK) (2002)			Book giving examples of different forms of narrative data transformation.	
59 Sava & Nuutinen (Finland) (2003)			Peer-reviewed journal article describing a dialogue between word and picture.	
60 Spry (NA) (2001)			Peer-reviewed journal article on performing auto-ethnography.	
61 Spunt et al. (NA) (1996)			Peer-reviewed journal article showing the development of an interactive videodisc programme for low back pain sufferers.	
62 Tilleczek et al. (NA) (2004).	Based on 60 interviews: 30 with parents of children with mental health issues and 30 interviews with service providers.	Recently completed documentary film.	Conference paper.	