

Service User Involvement in Developing NICE Guidelines:

Bridging the Evidence – Experience Gap

by

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Volume I

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Introduction to the Portfolio – Volume I.

This Portfolio contains work completed during the PsychD Clinical Psychology Course between 2005 and 2008. This Volume (Volume I) comprises three dossiers of clinical, academic and research based work.

The clinical dossier consists of six summaries of clinical experience obtained on six placements undertaken as part of the training programme, and summaries of the five clinical case reports completed on placement.

The academic dossier contains three problem-based learning accounts, three summaries of case discussion group process accounts and two essays.

The research dossier contains a service-related research project, the abstract of a qualitative research project, the major research project and the research log checklist (the latter being a summary of research skills acquired during training).

Academic Dossier

'Can the Experience of Hearing Voices ('Auditory Hallucinations') be Considered an Ordinary Part of Human Experience? What Implications might such a Conceptualisation have for the Ways that Clinical Psychologists Respond to Service Users who Hear Voices?'

Essay

December 2005

Year 1

Can the Experience of Hearing Voices ('Auditory Hallucinations') be Considered an Ordinary Part of Human Experience? What Implications might such a Conceptualisation have for the Ways that Clinical Psychologists Respond to Service Users who Hear Voices?

Introduction

Why Explore Auditory Hallucinations?

One of the most prevalent problems for people accessing mental health services is that they are 'socially excluded' - voice hearers ('hearers') are often perceived as dangerous due to the media's skewed reporting of command hallucinations. As a clinical psychologist I will necessarily come into contact with people experiencing voices so having a clearly thought-out approach will be of great benefit. Also I have personal experience of hearing voices and would like to articulate and refine my interpretation of how this tessellates with the life I have led since¹. Leudar and Thomas (2000) cited in Jones *et al.* (2003) state that psychologists need more patient accounts of the experience but I do not intend to present a one-sided and overly personal account - instead to highlight and link issues that seem to me under-emphasised in the literature I have encountered so far.

A Summary of my Reasoning

Many people hear voices; they can cause distress and lead to social isolation. Voices may reflect and impact upon wider issues in the individual's life so responses to them by both service user and provider can have far-reaching effects. Some hearers do not experience distress but incorporate their understanding of their voices into adaptive existing or emergent belief systems. These beliefs - for both distressed and non-distressed hearers may be regarded as delusions so whilst hearing voices as a phenomenon should perhaps

¹ I have chosen to use the first person in this account to integrate my personal experience and understanding with that of researchers in the field and differentiate my opinion from theirs.

be seen as 'ordinary' there are circumstances when the belief systems surrounding them necessitate intervention. Attention should therefore be paid to the interpretation or 'meaning' of the experience and the relationship people have with their voices. There are differing ideas as to whether enabling the service user to accept their 'situation' is likely to have a positive outcome and if so how to effect this. Given the impact voices may have on individuals' interpersonal lives I conclude that the therapist's response in terms of developing and maintaining the therapeutic relationship should be individualised and non-oppositional.

Selecting and Deselecting Areas to Cover

The scope of this question is vast so it is necessary to focus on a narrow selection of the many possible interpretations. Given the above I will focus on how the relationship people have with their voices may be aligned with other 'ordinary' relationships. Defining this term is however more of a philosophical than a psychological endeavour. I will also look at the ways therapists may react to service users in terms of the immediate demands of the interpersonal relationship, and the consequences or implications these may have. Though cognitive models will be discussed, this will be in limited detail as I choose to interpret the terms 'respond' and 'conceptualisation' to be more flexible and subtle than more formal UK notions of 'intervention' and 'formulation'. These more abstract components of interaction may underpin or convey the essence of 'treatment'.

What do voices represent? Can this be seen as 'ordinary'?

Does Frequency imply 'Ordinariness'?

Hearing voices is a common occurrence as many researchers have demonstrated. High levels of self-reported voice-hearing exists with Nelson (1997) cited in Lakeman (2001) reporting rates of more than 70% being found. More conservative estimates put the figure at around 4-5% (Tien 1991, cited in Nayani and David 1996). Not all of these people have or will be identified as having a mental health problem. It could be argued that the

incidence itself renders the experience 'ordinary'. 'Mental illness' is also common in these terms with 1 in 200 adults experiencing severe problems and depression, anxiety and phobias affecting up to 1 in 6 of the population (Singleton *et al.* 2001 cited in the Social Exclusion Report 2004). However the reaction of the wider general public and often the individual are of fear and intolerance. So neither voices nor mental illness are generally accepted as 'ordinary' Graham Cockshutt (2004), himself a hearer describes his experience that the label 'voice hearer' to most signifies someone who is 'violent, unstable and should be locked away' (p9). Ritsher *et al.* (2004) describe hearing voices as the 'most pathognomic symptom' (p.220) – the one most likely to lead to a psychiatric diagnosis. The British Psychological Society outlines that psychotic symptoms (which would include voices) are the 'severe expression of states that are present in the general population'. – A difficulty is in separating 'eccentricity' from 'psychoticism' (BPS 2000). It is here that exploring the meaning of voices can indicate to the therapist and hearer alike whether it is an ordinary experience and whether and how to intervene.

Romme and Escher (1993) point out that though 'admitting' to hearing voices is usually taken as an indication of psychosis or other mental health issue, the 'Reduction of hearing voices to the status of mere pathology is not very fruitful in helping patients to deal with these experiences' (p.25). The use of the term 'patients' here is interesting, as in other cultures receiving voices is revered. Sodie (1995) cited in Jones *et al.* (2003) points to the Xhosa culture where voice hearers are systematically trained to be indigenous healers. Other societies view hearing the voices of recently deceased relatives as being a natural part of the grieving process (e.g. Grimby cited in Ritsher *et al.* 2004). I will concentrate on western understandings of auditory hallucinations, often not as inclusive as those in developing countries, as this is the context in which I will practice. This discourse will look briefly at one western religion - Evangelism.

Issues of race are relevant within any diverse society however, and it has been found that the 'point prevalence' (p27) for hearing voices in 2002 (Johns 2002a cited in Wykes 2004) was 4% for white people, 2.5 10% for Caribbean people and 2% for Asian respondents. There have been attempts at understanding this difference (though the

example given here does not differentiate between people with or without a psychiatric diagnosis). James (2001) reported young Asian men themselves with broad Cockney accents hearing voices displaying the accents and even the language of their less anglicised minority group. Cultural issues (and perhaps gender) may then be linked to individuals' perceptions of the origin of voices and attributions made of them as 'dominant' and the reaction these beliefs generate.

What Function do Voices Fulfil?

If voices are to be construed as an ordinary phenomenon it is helpful to explore the roles they play. Hearing voices is for many people an experience so vivid that an interpersonal relationship with the voice(s) develops which some people may substitute for other, inadequate relationships in the individual's life (Benjamin 1989 cited in Hayward (2003). I feel it is difficult to separate cause from effect here as distance from more typically functioning people has been seen to be linked with less capacity for reality testing, thus sustaining delusional explanations (Beck & Rector 2005). Voices may remain the only source of validation, company or empathy an individual receives in a turbulent and confusing time so sustaining the relationship could be difficult to resist. Romme and Escher (1993) assert that it is important to see the perceptual position of the voice hearer. They recommend trying to understand the suffering the hearer's reality may cause. The relationship an individual has with his/her voices may be similar to their other interpersonal relationships so exploring these dynamics may indicate whether social skills training could be helpful.

The Significance of Voices

I contend that hearing voices is a state that should be 'normalised' – removed from the realms of the fearful and bizarre and accepted by the general population. Though it may alienate the general public it is an experience that can have great meaning for the individual. To help rationalise voices it is helpful to consider how hearers themselves understand, integrate and in effect 'normalise' the experience. Haddock and Bentall in

Romme and Escher (1993, p.212) state that 'auditory hallucinations generally have some special significance or meaning for the voice hearer, in this light only those techniques which explicitly address the meaning are likely to enable the hearer to take ownership of them as being a part of him or herself'. This view has been a relatively recent development though some relatively contemporary researchers (e.g. Berrios (1991) – cited in Jones *et al.* 2003) maintain the biomedical view that voices have no meaning.

I think that it may be difficult to gain the trust and respect of an individual without acknowledging the personal consequences of their voices. Wykes (2004) outlines that voices are influenced by interpersonal social as well as intrapersonal (e.g. belief structures and personal attitudes) constructs. 'Peg', a hearer working with Thomas *et al.* (2004) felt that understanding her voices would mean more effective coping. Leudar and Thomas (2000) cited in Thomas *et al.* (2004) suggest this understanding was gained by considering biographical events and the nature of her religious beliefs. This may be a generalisable phenomenon. Ron Coleman concurs, stating 'it became clear to me that I wasn't mad, and that the voices were there because of what had happened to me' (in James 2001 p.99)

How do Service Users themselves Manage their Voices?

Davies *et al.* (2001) studied people hearing voices who were described as psychotic or 'evangelical' (having strong religious beliefs). They found that 'evangelicals' had a more positive view of their experiences, and cited Fulford (1989) who argued that when voices are seen as a spiritual experience they are viewed as adaptive and life enhancing whereas 'psychotic' people were likely to experience negative social and behavioural consequences. Wykes (2004) feels that the difference between people whose voices are pathologised and those who are not is that the latter have belief systems that have adapted to the phenomenon. Thus voices may be heard without causing distress to the individual though the issue of general social acceptance perhaps remains. Jones *et al.* (2003) also found that non service users who heard voices didn't perceive them as frightening, but

asserted that one theoretical standpoint is insufficient to explain or engage with the experience of a relatively large proportion of society.

If service users themselves can cope with their voices it indicates that others should perhaps see them as acceptable. It is helpful to examine hearers' own meanings and coping strategies. Graham Cockshutt (2004) states that his 'compliance' [*sic*] with medication has been useful but complemented by other methods, breaking down the experience to separate 'compartments' that may not have to be visited for example. Other strategies include consciously rejecting the urge to attend to the voice, perhaps the reverse of the 'cocktail party phenomenon' (Moray 1959 cited in Hewstone *et al.* 1988) and distraction, by using a personal stereo for example.

What Understanding of Voices do Therapists have?

Psychologists have sought to explain the processes underlying voice hearing. Ritsher *et al.* (2004) outline that auditory hallucinations are often precipitated by stressors such as bereavement, trauma and fatigue. Thomas *et al.* (2004) echo the notions rooted in criticisms of Cartesian dualism that it is not presently possible to separate the 'physical' from the 'mental'. It has been observed that service users can hold contradictory beliefs simultaneously about their voices – in remission hearers may accept they are 'ill' and the voice is a symptom despite continuing to assert that the voice is a real 'other' (Ritsher *et al.* 2004). In my personal experience I have witnessed a young voice hearer pleading with her voices to go away as they mean she is not very well. I think this sums up the nature of voices – that they can seemingly understand and respond to conversation and 'external' events may be why people often attribute 'independence' i. consistency and autonomy to them.

Garrett and Silva (2003) suggest that voices are a breakdown in the monitoring of inner thought with a problem in monitoring speech as internal or external. Other theorists postulate that voices are the result of the 'subvocalisation' of inner speech' e.g. Frith (1998) cited in Garrett and Silva (2003). Bentall, Haddock and Slade (1994) cited in

Jones *et al.* (2003) offer another description of the 'externalisation of inner thought' theory in stating that hearers are detaching from mental occurrences that are seen as jeopardising the individual's wellbeing. A therapeutic approach could involve enabling the person to identify the source of the voice as internal or external to aid the individual's management of the experience (BPS 2000). England (2005) outlines that nurses 'might consider ways in which to support the integrity of a voice hearer's inner life and help the voice hearer derive coherent representations of the body and sense of self' (p32) I would add that for psychologists, caution is required in modifying beliefs that may have supported an individual's view of self or the world for some time.

Hoffman and McGlashon (1997) cited in Garrett and Silva (2003) assert that voices arise from disordered speech perception whereby verbal memory creates disordered 'linguistic expectations' (p446) where words are perceived with no sound. I find this unconvincing, as voices for me and for many others are articulate and novel. However it is possible this is an artefact of verbal working memory. More philosophical writers have argued that voices are a consequence of the 'embodiment' of the past in the present as happens in a physical sense to amputees continuing to feel sensation in amputated limbs (Merleau-Ponty cited in Thomas *et al.* 2004 p17). The notions of voices as misperceptions of the inner voice resonate with myself. I found the idiosyncratic and complicated observations voices I heard made of people and events around me highly amusing as they 'hit home' and were aligned with my own sense of humour. Similarly, people hearing commentaries of their thoughts or actions could be sensitive to this inner voice. The notion of the past interacting with the present is for me an incomplete interpretation though it may open doors to ways therapists can enable their clients to predict, understand and manage the feelings that voices evoke.

What Implications do these Explanations have for Clinical Psychologists?

Though these models may foster understanding of auditory hallucinations it is for the psychologist to enable hearers to maintain manageable cognitions about their voices. This necessitates collaboratively modifying unhelpful beliefs whilst minimising harm resulting

from beliefs being challenged but not adequately redefined. Wykes (2004) argues that as voice hearers' relationships with their voices evolve over time (reminiscent of most interpersonal relationships) these relationships may be 'malleable' (p26) and susceptible to treatment. Clinical psychologists are in the unique position of being able to apply the understanding of 'typical' human interactions and mental life to people with positive symptoms. I contend that the individual's explanations and coping strategies as well as the context of their life history should be paid close attention to and not sidelined or immediately pathologised. Merely telling someone not to take voices seriously as they are a symptom is likely to add to existing dysphoria.

Are Voices an Artefact of 'Ordinary' Social Relating?

Deegan (1996) cited in Garrett and Silva (2003) says that voices have compelling emotional valence and respond as real people. Leudar *et al.* (1997) and Nayani and David (1996) among others postulate that the relationships people have with their voices mirror those with people in the 'outside' world. That is people who adopt submissive interpersonal roles generally will experience voices as threatening and dominating. Birchwood *et al.* (2000) cited in Hayward (2003) also suggests that the power or 'omnipotence' people ascribe to their voices reflects that power they perceive in significant others. This allows psychologists to develop ways of ameliorating distress resulting from voices – a starting point being to understand the relationship they have with them rather than treating this aspect of the experience as irrelevant. There may be a danger of colluding in someone's hallucinations and associated delusions, but again if there is distress it is the psychologist's role to decrease it - perhaps by moderating this relationship. Discussing the ordinariness of a voice-hearing experience may enable the individual to identify where the voice is coming from and enable them to adapt accordingly.

Birchwood and Chadwick (1997) describe the phenomenon of omnipotence in more detail. They describe that varying affective reactions to voices are derived from beliefs about their power and authority rather than content. Perceptions of 'omnipotence'

(Cheung *et al.* 1997 cited by Wykes 2004) and power and authority (Birchwood and Chadwick (1997) are reputedly related to the degree to which people comply with their voices. Compliance with command hallucinations can potentially lead to voice hearers putting themselves in situations that jeopardise their safety and that of others. This indicates that assessing beliefs about voices and hearers' interpersonal relationships with them is vital. Vaughan and Fowler (2004) suggest that people tend to comply with voices they trust, implying that the relationship is perhaps more complex than merely command and obey, adding to the evidence for hearer – voice relationships being mediated by or similar to other relationships. It is important to remember however that a significant proportion of people do not experience their auditory hallucinations as they do other interactions. Hearers who believe their voices are 'supernatural' or 'omnipotent' (e.g. that of God) are unlikely to have an 'ordinary' relationship with them.

Understanding the relationships people have with their voices is important if the therapist is to be fully empathic and intervene effectively. Benjamin (1989) cited in Birchwood and Chadwick (1997) identifies it as being linked to schemata about social relationships. I contend that examining 'transference' would aid such understanding. Birchwood and Chadwick continue by describing the notion that an individual's aversive life history can greatly influence their negative relationships with voices (citing Goddard *et al.* 1996). However I wonder how positive relationships would be accounted for given that some people experiencing difficult childhoods may have more benevolent relationships with their voices and vice-versa.

Can Voice-Relationships be Normalised?

I feel strongly that it is crucial to decrease the stigma that voice hearers experience to improve social networks and support. The media is often responsible for misleading the public as to the extent of violence that voice-hearers perpetrate. To see voices as ordinary may decrease the threshold that people have for help-seeking. Normalising the experience may be an unrealistic ideal but can only improve social integration and hearers' mental health. I contend however that it is crucial that clinical psychologists remain highly

sensitive to the barriers between colluding with a client and being mindful of their respective worldviews. The present question refers to hallucinations but I feel it is difficult to separate the experience from the explanation, the hallucination from the delusion. A dilemma exists as to whether people who have certain beliefs but are able to coexist with their voices should be pathologised and in turn stigmatised. I believe that the relationship if not the phenomenon may be a consequence of other relationships and as such a useful vantage point from which to intervene.

As described earlier, some voice-hearing evangelical Christians are able to continue to function and remain relatively stress-free as they have a positive relationship and belief system surrounding their experiences. With voices having such meaning for the individual I feel it is incompetent not to assess in detail the causes and effects of their experiences. Fully examining voices and related beliefs enables the clinical psychologist to get to know the client holistically and where necessary, to encourage change in the ways they relate to and see themselves and others - which is likely to affect whether voices are experienced as disabling. Applying principles of social interaction and working on hearers' relating styles may help them manage their voices. It is unlikely that voices that are resistant to medication would be completely halted by psychological intervention but they may be amenable to decreasing associated distress. Wykes (2004) reports Pantellis and Barnes (1996) finding that 25 – 50% of patients' voices seem to resist 'adequate levels' of medication (p25). Cognitive Behavioural Therapy aims to 'teach people to swim' when it is not possible to 'turn the tap off' and it would be remiss to leave such a powerful window into the extent and nature of someone's distress unexamined.

What are the Treatment Implications?

Birtchnell (1996; 2002) cited in Hayward (2003) states that some hearers distance themselves from their voices to protect themselves and will remain suspicious of and uncommunicative with them. However Vaughan and Fowler (2004) found support for the idea that distance implies the voice is 'malevolent' but don't indicate whether this is a

cause or effect. Increasing the distance between voice-hearer and their voices could be a useful therapeutic technique though it could compound the problem. One distancing approach could be to reinforce to the person that their voices are not real and shouldn't be attended to. However the intimacy and personal relevance of the content of voices would mean that this could be counter-productive to the individual.

Intimacy is a potent product of voice – hearer relationships. This may be characterised by people relying on voices in making daily decisions (Romme & Escher 1993) or in the extent of information that the voices 'know' about the person (Romme & Escher 1994 cited in Birchwood & Chadwick 1997). This can manifest itself in running commentaries on behaviour of the individual but also lends itself to the description of relationships with voices as being reciprocal. Romme and Escher (1993) relay the experience of many hearers that voices are able to respond to the content of conversation with people outside of the hearer –voice relationship. Leudar *et al.* 1997 found this was 'relatively rare' (p892) though some people are able to negotiate with voices and agree times when they are to be active which was found to correspond with greater coping.

Should Therapists Intervene in an 'Ordinary' Experience?

'You believe in a God we never see or hear, so why shouldn't you believe in a voice I really do hear?' (Patsy Hage quoted in James 2001 p. 31). This logic may seem justifiable terms for not trying to change anything in the situation, particularly if the voice is perceived as 'spiritually enhancing' or as a 'voice of conscience' (Nyani & David 1996). Ritsher *et al.* (2004) found that 10% of hearers described their voices as comforting or advising, indicating a significant proportion of the voice-hearing population. However hearing voices can be a horrendous experience; typical reactions include fear, anger, intimidation and guilt. It would always be appropriate to intervene to ameliorate this distress or enable the individual to manage it. However unless the person is in distress, dangerously far removed from reality and/or socially distant or hypermanic as a result of their voices or delusions I don't believe intervention should be mandatory. I feel social disability and subjective distress should be the guideline - if people can happily coexist

with their voices e.g. as the 'spiritual guide' that some researchers (e.g. Romme & Escher 1993) have found they should not be stigmatised.

So what *Should* Therapists do?

There are several options open to the clinical psychologist presented with someone hearing distressing voices. Collaboratively exploring their voices' meaning in an attempt to 'normalise' or perhaps 'neutralise' the experience is one option that could lead to a mutually respectful and productive relationship. Another could be to ignore the emotional significance and message voices convey. However I believe this would lead to distress and an unwillingness to confide in the therapist. Haddock and Bentall, cited in Romme and Escher (1993) divide coping strategies into 'distraction'; 'focusing' and 'anxiety management'. They further outline several approaches to help individuals manage their voices themselves. 'Curing' them may be difficult so coexisting and feeling in control of them would seem to be an advisable and workable compromise. Diarising and reflecting on voices has been received well by some of Romme and Escher's clients, they indicate that such monitoring or 'focusing' on voices is a good starting point for therapy sessions where the individual finds it hard to talk about their experiences. They state that diaries enable communication with voices which in turn is 'one of the most important and successful means of finding some order in an otherwise chaotic experience' (p200).

Romme and Escher (1993) also advocate group work as a means of support, of sharing coping strategies and a sense of alliance or 'companionship'. This could be subsumed under the category of anxiety management as well as social skills training as people could be aided to view their experiences as less bizarre, medicalised and insurmountable. Group situations may also be good for improving social skills that can be used in dialogue with voices. Anxiety management via relaxation techniques could be seen as a 'sticking plaster' but is a necessary skill easily imparted by clinical psychologists. I feel that though distraction may be a useful 'on the hoof' technique it only decreases distress temporarily, though topically and may increase the extent to which the person feels alienated – both from the voices they are attempting not to attend to but also society they

may feel rejects their experience. However distraction approaches would perhaps be a useful addition to a self-management toolkit.

Implications for Therapists' Social Skills

At the start of this discussion I stated that I would concentrate on interactional ways of responding to service users who hear voices. I suggest that clinical psychologists should assiduously seek to employ features of positive therapeutic relationships such as 'transference' and 'modelling' and an awareness of the principles of social psychology. In order to increase 'face validity' of the therapist's stance on the client's problems and build a therapeutic alliance psychologists may provide psychoeducation and information about prevalence, causes, coping strategies (including psychological approaches such as cognitive behavioural therapy) and the use and impact of medication.

There are further ways in which the therapist can build a positive relationship – by collaboration rather than pathologisation. Ritsher *et al.* (2004) integrated the approaches I have described above and suggest the following process be employed. **V** -Verify it is really a voice; **O** - Origin – bereavement or brain injury etc? **I** - Impact – are they distressing or command focused? **C** – Culture- which norms exist in the individual's original culture? **E** Educate **S** - Strategise with the individual and their significant others.

Romme and Escher (1993) quote a service user who described an effective clinician -'the most important thing she did was that she was honest – honest in her motivations and in response to what I told her' (p.228). Romme and Escher suggest further effective responses to people presenting with voices - outlining ground rules early on, making and maintaining safe space, empowering the client to set the agenda and their goals and being open about personal feelings. I would summarise these as taking a collaborative and personalised approach and a sound basis for cognitive behavioural techniques.

Conclusion

Throughout this discourse I have tended to refer to 'hearers' when taking the client's perspective and 'auditory hallucinations' when assuming the role of clinical psychologist. I think this is an important distinction. Academically, voices are likely to be hallucinations but they can seem ordinary and 'real' to the client and can in turn have distressing or helpful input into the psyche of the individual experiencing them. It is not always helpful to communicate the 'academic' features of relationships between voices and hearers when aiming to enable the hearer to reformulate his or her own belief systems and interpersonal style. By taking the time to ensure the relatively straightforward 'ordinary' principles of therapeutic engagement and respect are implemented for voice hearers and their voices the clinician can bring many instrumental data to light. These can then help the therapist and client collaboratively decide which of the more formal psychological interventions (if needed) may be most relevant or effective. In all interactions with people it is vital to remember the importance and implications of individuality and to respect this by continually reformulating the way each client and each individual session are thought of. The principle of honesty is vital but perhaps not absolute. Working from the hearer's perspective may necessitate compromises and reformulating cognitions so that they are adaptive beliefs, not absolute truths. I feel that being oppositional and identifying the experience as merely a bizarre symptom will serve only to distance the client from the therapist.

I believe hearing voices should be 'marketed' as an ordinary experience to the general public and to those service users for whom it is appropriate. This is because they are commonly encountered and not necessarily a sign of mental ill health (which is, and should be regarded as, another typical human experience). The delusions surrounding voices are more variable however and should be explored to uncover whether they are 'adaptive' or leading to distress and /or risk. The decision as to whether the delusions are adaptive is a cultural and an academic one.

If voices do or are likely to jeopardise the social, physical or psychological wellbeing of the hearer or others the therapist should, without exception intervene. The implications for the hearer to see voices as ordinary are to improve self-concept and make it easier to accept and benefit from help with issues voices raise. For clinical psychologists seeing voices as ordinary means that some people may have a powerful experience reduced to a stigmatising symptom whose meaning is disregarded. Portraying voices as a distinctive or unusual occurrence may too leave a person feeling dysphoric - stigmatised or resistant to engaging. I believe the ordinariness or acceptability of a person's voices cannot be generalised and should be thought out differently for each individual. A good rule of thumb would be that creating a space in which the psychologist and hearer can identify information about the client's voices, social and familial relationships and other biographical data can aid therapeutic engagement and understanding and inform decisions about interventions.

Reflection

I now regard beliefs about voices and people's relationships with them as even more complex than I originally thought. However I feel this is positive in leading me to attend to my clients rather than my preconceptions.

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'Using Illustrative Examples, Discuss the Advantages and Disadvantages of Formulation to Clinical Psychology Practice'

Professional Issues Essay

January 2007

Year 2

'Using Illustrative Examples, Discuss the Advantages and Disadvantages of Formulation to Clinical Psychology Practice'

The History of Formulation

Clinical psychology is a relatively new discipline, within which formulation is a relatively new concept, first being mentioned in the 1950s (Crellin 1998). Formulation 'formed the basis for the profession's distinctiveness and autonomy within the NHS, and ultimately came almost to define the profession' (Crellin 1998, p18). In this synthesis of the relevant literature I² will attempt to elucidate the advantages and disadvantages and examine the usefulness of formulating individual clients' problems using examples from the literature and aggregated examples of people with whom I have worked³.

There is a distinction to be drawn between advantages and disadvantages for clinical psychology and for clinical psychology practice. As suggested above, formulation has been key to clinical psychology's status as a profession. Arguably this does affect day-to-day clinical practice as much as 'Agenda for change' has influenced the way that clinical psychologists are regarded within multi-disciplinary teams. This is however a political point and the bulk of this account will concern the ways clinical psychologists provide therapy on a day-to-day basis.

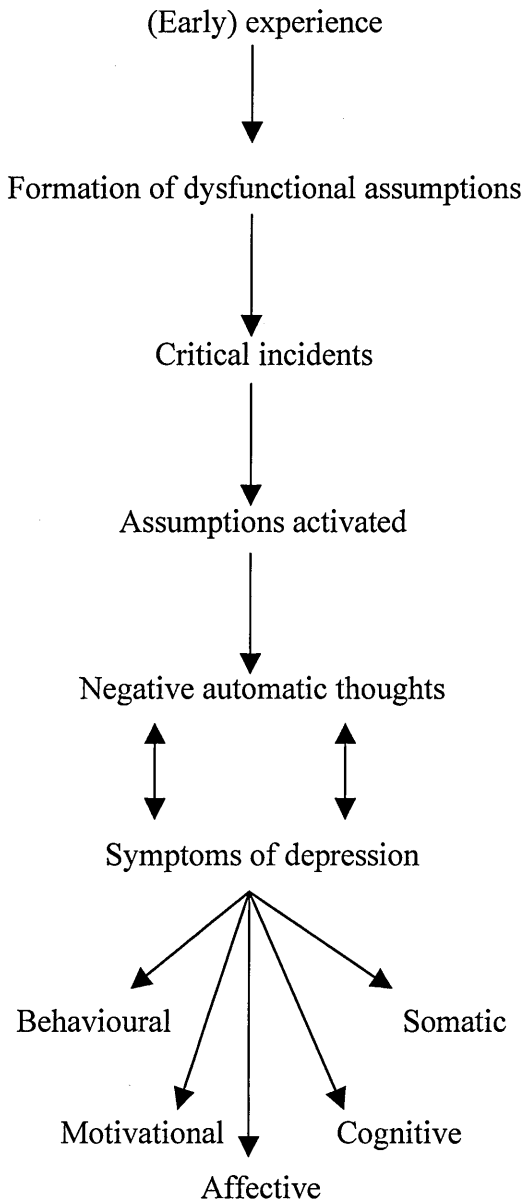
Definition of 'Formulation'

In order to determine its value it is important to define what I mean by the term 'formulation'. Cullen and Combes (2006) state that formulation requires an analysis of behaviour now and in relation to environmental events and behavioural history. Tarrier (2006) describes formulation as testing hypotheses and translating theory into therapy. Kuyken (2006) believes that formulation is the link between theory, practice and research. Sim *et al.* (2005) add art to the areas formulation unites. For Cognitive Behavioural Therapy (CBT), Kuyken (2006) feels formulation involves describing the

² I will use the first person in this account to emphasise the role of my own thinking on this topic as individuality is germane to this debate.

³ This is to preserve confidentiality and avoid plagiarism or infringing copyright laws.

presentation and predisposing factors (both recent and distal) as well as perpetuating and maintaining factors. An example of a well accepted format is given below, in Beck's (1967) model of depression cited in Hawton *et al.* (1989 p171).



There are many different therapeutic orientations within clinical psychology – CBT, systemic therapy and psychodynamic therapy being the most prominent. To examine each approach individually would result in an account spanning several volumes.

Therefore I intend to use varied examples and discuss formulation in terms of general principles.

The term 'formulate' itself is defined as 'to reduce to or express in a formula, set forth systematically' in the Oxford English Dictionary (Onions, 1986 p386) thus emulating psychology's aspirations towards science, perhaps illustrated by the zeal with which psychologists embraced quantitative research methods. I believe that condensing people to numbers is problematic- even with advances in the statistical methods available. Anecdotally many trainee clinical psychologists choose qualitative methods for their doctoral research projects to avoid this reductionist dilemma. Mace and Binyon (2005) assert that though formulations are unique to an individual it is possible to follow them in a systematic manner though the discussion below casts some doubt on this assumption.

Features of 'Good' Formulations

To evaluate formulation it is useful to start by looking at the optimal versions. Ivey (2006) lists the following as making for a good formulation: conciseness, an account of the individual's vulnerability to the disorder developed and why it emerged at the time it did, what maintains it, what the individual's probable response to treatment would be and finally that it gives the reader unfamiliar with the case a full and comprehensive appreciation of the person's problems relative to their early relationships and life events. For example a young woman whose parents were rather conservative previously had many sexual partners then became pregnant with her long term partner. She developed health anxiety and intrusive thoughts about passing on Acquired Immune Deficiency Syndrome (AIDS) to her unborn child. The formulation involved the notion of guilt in the context of her sexual activity as rebelling against her parents' values and the resultant notion that she was tainted. The health anxiety and intrusive thoughts made sense to the individual who had experienced anxiety about her parents' reaction to her not marrying her partner. She misinterpreted feelings of anxiety as symptoms of illness and felt an inflated sense of responsibility for the wellbeing of her child. As such this formulation

met the criteria listed above and led to motivation and engagement in the CBT that followed.

Bieling and Kuyken (2003) state that a cognitive case formulation refers to the individual's *problems* rather than to the whole person. It is of course impossible to describe these without reducing an individual's experience, life situation and predictions of their future to a few statements. Some authors argue that this is objectifying for the client and may seem overly simplistic as it 'unavoidably totalises and reduces' (Crellin 1998). It is a narrow balance to include enough information to make the formulation individualistic and comprehensive but not so much detail that the essence is lost (Sim *et al.* 2005). Ross (2000) states that the challenge is to develop a formulation that is a synthesis rather than a summary and goes on to clarify that it should tell a story. Formulation is a way of drawing together elements of a person's situation. As such an advantage may be that it localises the problem and speculates about its progression. The apparent disadvantage is that the client may be left uncertain about how other facets of their life fit in.

Other commentators have written on the subject of elements of good formulation. Harper and Moss (2003) add that formulations should be grounded in what the client has said as opposed to the therapist's interpretations. They also cite Yardley (2000) in saying that good formulations should be transparent and coherent. Sim *et al.* (2005) argue that a good formulation 'capture[s] the essence of the case...include[s] presence of a theoretical basis, sensitivity about the patient and specificity to the patient' (p290). Together this literature suggests that clients should be the audience as well as the subject for formulations – that they should be meaningful in the context of the client's life and not riddled with jargon. Gardner (2005) tellingly asks whether the therapist is 'audience, editor or translator' in developing formulations about clients. (p11). Though this list of features paints formulation as straightforward and useful, it is unclear as to how it is actually utilised on a day-to-day basis. In practice there may be so many criteria to fulfil that the formulation is always 'technically' flawed or deficient. As such these lofty ideals

may not translate into improved practice, but arguably they should remain as goals nonetheless.

From Theory to the Individual

Formulation is ideally underpinned by theory. Persons (2006) describes the means by which therapists can use nomothetic research evidence to inform idiographic case formulations. As such cognitive behavioural models of panic (eg Clark 1986 in Hawton *et al.* 1989) can be used to describe an individual's presentation – for example, the client whose parents were involved in crime and who came to see the world as dangerous, feared attack when going outside leading to catastrophic thoughts and the overwhelming compulsion to stay at home. Persons (2006) argues that the idiographic description of the origins and maintaining factors of a problem means that the formulation approach is flexible but that this can be a disadvantage if the model is applied in a non evidence-based way. For example in the situation described previously, if the presentation of symptoms were consistent with post-traumatic stress disorder, the avoidance behaviour may be similar but treatment based on an amalgamation of models would not be accurately evidence based. Again the issue of reducing models to individual cases means they have to be adapted thus the flexibility of formulation may be confounded by the rigidity or absence of critiques of their underpinning models. Harper and Moss (2003) view the flexibility of formulation as uniting different branches of clinical psychology under one umbrella. Therefore flexibility seems to be both an advantage and a disadvantage.

Different Approaches to Formulation

Crellin (1998) argues that formulation is not compatible with the therapeutic modalities that privilege phenomenological experience as well as observation. Thus it may be a disadvantage as mythology and complex terminology may be problematic for the client. For example consider a middle aged man, previously overprotected by his parents who begins exhibiting obsessive-compulsive symptoms involving repeatedly checking the gas

stove is off, after his father develops lung cancer. He may not respond positively, at least initially, to being contrasted with Oedipus, reacting to repressed wishes to suffocate his father and gain possession of his mother. These interpretations are perhaps harder to justify empirically than more concrete formulations such as those derived from a cognitive behavioural perspective. However as Ivey (2006) insists, modern psychodynamic formulations are becoming more linked to client's own language and views and 'less speculative and intuitive'. (p324). There is also recourse to explaining formulations with differing levels of complexity as therapy progresses.

Various formulation systems may coexist without the need for one to be right at the expense of the other. This could be a corollary of the 'same' mental illness having different expressions in different individuals. The difficulty may be in that there is no consensus as to what a formulation should 'look like' – even within a particular approach, such as psychodynamic psychotherapy (Mace and Binyon 2005). Other therapeutic phenomena known to improve outcomes such as 'rapport' remain similarly difficult to adequately define.

Inter-rater Reliability

If formulation is useful, surely it will differ little between clinicians. Bieling and Kuyken (2003) outline research regarding a formulation system - the Core Conflictual Relationship Theme (CCRT) and cite Luborsky and Diger's 1998 findings that it is a reliable and valid method, related to better treatment outcomes. Its interrater reliability ranged between $K=0.6$ to 0.8 (moderate to good) in their review of 8 papers. Some caveats need to be mentioned here however – the research was undertaken by the people who initially devised the approach. Also many formulations tend not to follow a uniform system, so those with heuristics are more likely to show agreement between clinicians.

Bieling and Kuyken (2003) outline agreement between raters in other contexts. They cite Beckham *et al.* (1984) who found 76% agreement in identifying cognitive mechanisms in clients selected independently by clinicians for study. Persons *et al.* (1995) were

discussed in the same paper and had found good agreement when presenting problems were identified but little agreement for deeper, underlying mechanisms and cognitions. In a later study, Persons and Bertagnolli (1999) cited in Bieling and Kuyken (2003) found reliability increased with the amount of training. Fothergill and Kuyken (2002) cited in Bieling and Kuyken (2003) found that, contrary to expectations, experienced therapists did not necessarily have greater reliability than novice clinicians.

This finding is contrasted with Eells *et al.* (2005) who compared expert, experienced and novice therapists from both CBT and psychodynamic orientations. Participants formulated 6 vignettes. This time there were significant differences between the experts' formulations which were more 'comprehensive, elaborate, complex, and systematic' (p 579) though they were not more linguistically precise or coherent according to judges. There were few differences with regard to the orientations to which the therapists subscribed.

The evidence so far is inconclusive, further 'scientific' enquiry is necessary. Kuyken *et al.* (2005) outline that even though two clinicians' formulations may be similar, that does not mean that they are necessarily valid. Once a 'valid' formulation is made it also does not necessarily mean the responsible practitioner can apply it in an effective manner – so being an expert formulator is not an advantage unless the individual has the skills to use it appropriately.

Evidence-based Practice and the 'Scientist-Practitioner'

The Department of Health is increasingly calling for evidence-based practice. Psychologists have been involved in developing mental ill-health related guidelines, for example those for the treatment and management of schizophrenia (Department of Health 2002). With clinical psychology's history of aiming to be a unique, evidence-based discipline as enshrined at the Boulder conference (Crellin 1998) these goals are complementary.

The accuracy of the theoretical underpinnings a formulation is built upon seems pertinent. As mentioned above, the scientist – practitioner model clinical psychology adopted after the Boulder conference (Tarrow 2006) portrays psychology as a reflective, evidence-based practice. If the conceptualisation of the individual's problem has been researched and critiqued in detail and is in fact accurate, one would think that treatment based on that understanding would in turn be useful. However Bieling and Kuyken (2003) assert that it is not conclusive that even cognitive therapy is effective merely because its theoretical account of the nature of psychological change are true.

The alternative to formulating each individual's situation may be to approach clients without any 'formula'. Wampold (2001) estimates that up to 70% of the variance of clinical outcomes is explained by common therapist effects alone. For example someone with social phobia may find the experience of being listened to and positively regarded and 'recover' as much because of having this space and time than to any specific understanding the therapist employed. Sabelli and Carlson-Sabelli (1991) state that '...a theory is required not only to interpret data, but also suggest which data will be collected' (p2). In other words without a framework we would not know what information to attend to in order to develop our 'blueprint of the likely targets to be addressed during a treatment' (Mace and Binyon 2005).

Harper and Moss (2003) describe how developing formulations can be 'fluid, messy' subjective and passionate' whereas the scientific underpinnings of evidence based practice suggests that it ought be an objective, elegant process. However as Denman (1994) outlines, 'The science of formulations must be combined with art. Something is lost if the formulation does not capture the essence of the case' – cited in Sim *et al.* (2005 p 289). This suggests that the psychologist must appreciate and capture the synergy of the individual being more than the sum of his or her parts. On this point the argument for formulation being the scientific expression of research is lost; instead it seems to be more the skilful, individualised application of aggregated knowledge. However it remains an advantage that psychologists are seemingly aware of the limitations of formulation and can use their research skills to recast their ideas in the light of new insights.

Criteria by which to Evaluate Formulation

Several authors have identified criteria or questions against which to verify formulation. For example Tarrier (2006) outlines that the test of formulation is a). How much it accounts for the individual's problems, b). its agreement with the client's account of the start of the problem, c). It results in testable hypotheses 4). The client's response to the shared formulation is positive. An example may be a client who presents with sleep problems and suicidal ideation after a spouse discloses an affair, which the client has not felt able to discuss with them. Exploration uncovers that the client's family of origin did not talk about emotions even after the parents divorced and the children experienced conduct problems at school. A formulation of this situation could articulate the client's fear that the family system cannot withstand the pressure that would result if the problem was aired. A sense of guilt and responsibility for breaking up the family may reside within the client who sees the links with the divorce in his childhood and the potential pressure on the children. The individual may react to this by assuming they are unlovable and ruminates on this – disturbing their sleep. The testable hypothesis here is that raising and working through emotions may benefit the relationship and relieve some of the problems the individual faces. Treatment could concentrate on the family system and the power and location of guilt and blame and the benefits of expressing emotion.

Rapport and the Sharing of Formulations

Formulation is often described as being important in developing a relationship with the client. Tarrier (2006) gives an example of the sharing of a formulation lessening rather than deepening rapport. It occurred within a psychosis group run by Paul Chadwick *et al.* (2003) whereby around half of the participants made negative comments about formulations focusing on the extent and ongoing nature of their problems. However some clients reported positive effects such as feeling reassured and hopeful based on having better understanding of their problems and being able to visualise a solution. Kuyken (2006) agrees that formulation is acceptable and useful if it leads to the client respecting the professional and if it progresses therapy but highlights that sometimes the facts used

to describe the formulation are those that the client has tried to avoid thinking about. For example a client who was belittled by her parents and was argumentative and controlling with her partner said she despised him on many levels for not arguing back. She was not ready to think of her parents as being anything other than supportive or her early experiences as leading to her actions in her current relationship and decided to terminate therapy rather than explore these options.

Tarrier (2006) describes an ethical obligation for therapists to share their formulations with clients so that the therapist's conception of the problem and the treatment plan are transparent. This would hopefully lead to deepened rapport. Bieling and Kuyken (2003) point out that explaining the formulation is not an integral necessity in CBT. Some authors believe that explaining the formulation can be an overwhelming and distracting amount of information to process (eg. Mace and Binyon 2005). Perhaps an individualised decision is necessary here.

Benefits to the Therapist

Some researchers (eg. Eells 1997 cited in Eells *et al.* 2005) have listed possible advantages of formulation as increasing therapist's confidence and empathy – it may be that the advantages for therapists may outweigh those for clients, who may feel objectified and overwhelmed with such information (Gardner 2005). Harper and Moss (2003) ask whether clients actually expect a formulation, and argues that many clients do not. However in my experience clients often seek help to understand their problem from another point of view, and look to the psychologist as expert to explain what is wrong as a precursor to 'making things better' as they might with any other health professional.

Formulation versus Diagnosis

Formulation may have an advantage over diagnosis – which may be what clients expect from an assessment. Mace and Binyon (2005) outline that mental health diagnoses do not say anything about the development of a disorder. Someone consulting a general

practitioner for breathing difficulties can expect that if they are told they have asthma, that the disorder had a certain developmental course and a particular biological substrate. This is not the same for mental health problems which are arguably less observable and concrete. Formulation may bring together elements of the disorder and explain as well as describe them. Kuyken *et al.* (2005) contest that when formulation moves from the descriptive to the explanatory it becomes less reliable – though one wonders what else would fulfil this function.

Eells (2001) in a paper describing the attributes of the Core Conflictual Relationship Theme method for developing formulations describes formulation as a core clinical skill that organises complex and sometimes contradictory information. With diagnosis, the more information gathered the easier it is to arrive at a conclusion, particularly because Diagnostic and Statistical Manual–IV (DSM-IV) lists criteria for different diagnoses – exhibiting a certain number of them earns the individual a particular label (Sperry 2005). However with formulation, a disadvantage is inherent in its flexibility. Often the more information that is gathered the more difficult it can be to arrive at an explanation that incorporates all of the data. There is then perhaps a disadvantage in the therapist actively seeking further details – which may lead to biases in making decisions.

The advantage that Mace and Binyon accord formulation in this context is that formulation and contingent treatment plans can be modified without the diagnosis being changed. This may serve to decrease confusion and add to the creativity with which the therapist can generate treatment plans with the client. This is echoed by Persons (2006) who reports Seligman's (1995) description of therapy as 'self-correcting' and adds that formulation allows the clinician to rely on principles rather than a set list of interventions.

Outcome Studies – Individualised versus Manualised Approaches

One way of assessing the advantages of formulation is to compare outcomes of individualised and manualised interventions. The former occurs when the therapist develops a formulation based on interaction with the specific client. The latter –

manualised interventions refer to programmes such as ‘Mind Over Mood’ (Greenberger and Padesky 1995) which provides a template for intervention with clients with particular diagnoses. This comparison would highlight whether the individual approach to formulation is superior to assuming depression for example is generic.

Schulte *et al.* (1992) (cited in Kuyken 2006) compared 120 people with phobias with one group being given a manualised exposure treatment, one group being given an individualised treatment and a control group being given treatment based on another client’s formulation. The results surprisingly showed that the manualised group outperformed both other groups, though it was postulated that the therapists could not avoid some element of individualisation even with a tightly controlled manualised programme. This shows support for treatment being evidence based but not necessarily individually formulated. There remains the question of whether treatment can be evidence-based if there is no formulation. Bieling and Kuyken (2003) state that ‘there is no compelling evidence linking cognitive case formulation to improved treatment outcomes’ except for one study acknowledging better ratings of the therapeutic relationship from the therapist. It must be borne in mind however that this relates to cognitive case formulation not necessarily other modalities. Another issue raised is that it would be hard for therapists not to individually tailor treatment at all as it is focused on interactions with the client - that are always going to have a unique quality. Though whether this would conform to the above definitions of ‘formulation’ is debatable.

Reliability and Validity

In terms of the reliability and validity of formulation systems, which Bieling and Kuyken (2003) propose as criteria for evaluation, it is key that two differing formulations of the same person can be equally valid. For example a therapist with a behavioural focus may concentrate on the gains a person accrues from performing a behaviour such as repeatedly headbanging. These gains could be seen as meeting a need for attention and self-stimulation. However a more psychodynamically oriented therapist may interpret the wish to self-injure as an artefact of the ‘deathmaking culture’, in that the person is

reacting to an internalised belief that they were an unwanted, damaged baby. Both of these approaches may yield positive outcomes.

In contrast, Kuyken (2006) suggests that in the case of CBT formulation, flaws in one part of the process do not necessarily mean the output is problematic. What I think Kuyken means is that the formulation can be piloted and tested with the client. This may be a testimony to its flexibility but on another more problematic note, it could mean that the formulation itself does not matter to the outcome. For example a therapist may overestimate the amount of influence moving house had to an adolescent and suggests this as a triggering factor in her eating disorder. The adolescent may refute the idea when postulated and sees it instead as a protecting factor. Other hypotheses may then be tested and if necessary eliminated. This may affect rapport or the pace of therapy but not necessarily the outcome. Another option is that formulation is irrelevant; that describing previous events as current problems is tautological (as suggested by Nezu and Nezu 1989a cited in TARRIER 2006) and developing the hypothesis that moving house triggered problems for the individual neither advances nor hinders the therapy. These disadvantages imply that formulation is not necessarily a reliable process.

Heuristics

There are ways that psychology research itself has identified that decisions including formulations are susceptible to bias. The main target of research in this area concerns itself with heuristics. TARRIER (2006) cites Nezu and Nezu (1989a) who outline that psychologists, as others, are not immune to availability, repetitive and anchoring heuristics, biased search strategies, overconfidence and hindsight bias. That is they may base decisions on recent clinical experience, making speedy decisions, using insufficient data when coming to a conclusion about a client, they may not employ flexibility in rethinking decisions based on new information, pay selective attention and seek confirmatory information rather than being open minded about a piece of information. There is also potential for psychologists to be 'cognitive misers' and not expend extra mental effort to find the best fitting solution when one they have is comfortable and 'will

do'. For example a clinical psychologist who has extensive experience of working in forensic settings and who has seen many clients with a history of neglect and abuse may find signs of this abuse in a new role in a child and adolescent mental health service. The relatively recent controversy over 'hidden' memories of child sexual abuse apparently 'uncovered' by hypnotherapists highlights the impact that such confirmatory biases or availability heuristics may have.

Given the complexity of human mental life both for psychologists and their clients it is perhaps unsurprising that such mechanisms are used. Kuyken (2006) outlines that given the cognitive load and the emotive nature of formulating, the use of heuristics is likely (citing Kahneman 2003). The pattern they typically follow however is likely to say more about the psychologist than the client. Spengler and Strohmer (1994) cited in Bieling and Kuyken (2003) found that therapists scoring lower on a task of cognitive complexity were more likely to use erroneous heuristics in formulating, suggesting a lack of ability rather than confidence resulting from wisdom. Waddington and Morley (2000) conducted some research into availability bias and found that there was no evidence of it appearing as a function of therapists' orientations. There were some methodological problems with a ceiling effect in the paradigm used but the authors concluded the paper by saying that 'clinicians showed scepticism towards their own initial ideas and endorsed a hypothesis-testing approach indicating the validity of individual formulation'. This seems rather a sweeping generalisation to make on the basis of some flawed methodology.

I wonder whether the use of heuristics is a complete disadvantage – it would be impossible to be completely dispassionate and the formulation may be more closely tied to the therapist's mode of treatment and understanding if he/she can think of the situation in his or her own terms. Many psychologists are followers of the social constructionist tradition which holds that there is no objective truth, merely that which emerges through discourse and which acknowledges the biases of the participants (as in qualitative analysis using grounded theory as defined by Charmaz 2003). Surely owning these biases and not denying them is the most pragmatic way forward – and would demonstrate to the clients of our services that psychologists too are human. If formulation is of

utility to the therapist perhaps it can withstand being couched in the terms most informative to the therapist.

Conclusion

Not all commentators are positive about the function and practice of formulating. Crellin (1998) quotes Shapiro (1959) who said that 'Any appearance of clarity and systematization is largely a retrospective phenomenon. The actual process of arriving at one's aim seems to be a muddled one'. Though this somewhat undermines the Boulder model of the scientist practitioner model it must be remembered that psychology has developed rather a lot in the last 45 years and that formulation too is likely to have progressed. Crellin, partly disparagingly goes on to state that 'in examining the profession's use of the term [formulation], what has emerged has been a mixture of vision, passionate belief and commitment, self-preservation and professional aggrandizement (1998 p27). Thus the political function of formulation may be key to its inception.

The scientific evidence for formulation is inconclusive at best, highlighting its variability. Formulation may act as a guideline for thinking about a client and providing a theoretical framework for information to attend to rather than being a rigid template. As such it has more therapeutic value than 'diagnosis'. Psychologists are interested in individual differences, formulation is perhaps the best vehicle to reflect this even without its practical mechanisms being uppermost. There are perhaps too many criteria to consider to easily meet the scientist's needs, and reducing a client's life to a short story of his / her problems is insufficient for more phenomenological practitioners. Trainee psychologists may find it impossible to reach the pinnacle of having 'accurate' objective formulating skills. With differences between professionals and orientations having a negligible impact on outcome there is no concrete method for verifying that any formulation is correct and makes a difference, even in research designs. Formulation has relatively few disadvantages if its claims to scientific rigour are tempered by awareness of the fallacy of reducing lives to discrete categories and the story it tells is seen as a starting point.

As such, in terms of clinical psychology practice, formulation is so elusive and ethereal that its effects can only be observed through the interaction the individual and therapist develop. My conclusion is that formulation is advantageous as it helps psychologists feel more confident through 'visualising' the individual's experience, and that in many cases it genuinely underpins their treatment approach in a way that generic models would struggle with. This effective, practical development of formulation may aid therapy but it is more of an art than a science.

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'The Relationship to Change'

Problem -Based Learning Reflective Account

March 2006

Year 1

Problem Based Learning (PBL) Presentation Reflective Account – The Relationship to Change

The Task

On starting the PsychD course, trainees were divided into groups of 7. An introductory workshop was devoted to the benefits and process of ‘problem based learning’ (PBL). Our ‘problem’ was to produce a presentation on the ‘relationship to change’ within 6 weeks. A ‘non-expert’ tutor would facilitate, but not lead, every other session. Group members would rotate roles of leader and scribe in different PBL assignments.

The Process

We⁴ focused on models of change that resonated with us regarding the transition into the course and into the roles of ‘trainees’. Though this was friendly, in retrospect we were facing an initiation into a team and needed to establish our individual roles and group identity. In hindsight it was reassuring to share a ‘common fate’ (Lewin 1948), which did foster some ‘togetherness’. Recently I have commenced therapy with several clients and have re-experienced directly and vicariously this uncertainty and insecurity. I refer to having to place salient aspects of your future (your mental health or career) in the hands of people you must engage with but may not yet trust. It is also expected that this engagement will be augmented by enthusiasm and motivation - difficult qualities to generate spontaneously. However withholding these could lead to a group member or ‘therapee’ being labelled ‘non-compliant’ or an ‘unsuitable candidate’.

Afterwards I recognised my participation as directive - repeating my opinion until it was considered though I could accept rejection. This still feels awkward though it mirrors my current therapeutic style. Though therapy with CMHT clients in Britain is necessarily more directive than that outlined in leading American textbooks, I still feel I work too didactically.

⁴ I will use the first person in this account to make the process of reflection more transparent

One client communicated that she regarded me as an authority to report back to about her progress. This highlighted differences in views of evaluation. Our group wanted to succeed but there was definitive right or wrong. I discovered that specific and detailed goals and for the individual to be 'in therapy' for themselves rather than to please others is vital.

I feel the change process the group underwent closely followed Tuckman and Jensen's (1977) model of team development as follows:

Stage 1: Forming

Joining a group provokes anxiety (Brown 1988), reminiscent of the tentative process of 'being socialised' into therapy. Initially in the group there was a process of establishing boundaries as trainees, similar to establishing myself as a competent, confident and trustworthy therapist. There may be problems with power and responsibility with clients initially feeling they are the only person gaining from the interactions, and assuming they need to please the therapist.

Sherif and Sherif (1969, cited in Brown 1988) outlined that groups' social structures lead to status differences and dynamic interpersonal relationships. People reluctantly volunteered for roles of leader and scribe. Being the first leader of a new group was a risk I chose not to take, perhaps later made tangible by feeling vulnerability as a new therapist negotiating intrinsic power differentials. It is a learning point for me to adapt to being a democratic and approachable leader and to trust the group to carry the task forward. This is reflected clinically in my need to learn to trust the client to have their own solutions to their problems as enshrined in client-centred therapy.

The group launched with a sense of motivation and purposefulness. However discussions were nebulous, everybody trying to establish some semblance of an approach, each promoting their own definition of 'change' and sharing frustration at the abstractness of

the question. The chair had to summarise to move us forward which meant not considering each contribution in depth.

Stage 2: Storming

'Storming' accurately describes us being overwhelmed by the task at hand – each seeking to understand whilst trying to sound knowledgeable. I have felt this in therapy – trying to sound confident and competent whilst feeling unsure and confused. In the group, though plans emerged laboriously, ideas started feeling germane and we began to agree. Work started feeling focused and productive, with recognisable outcomes and components. Momentum built with grand new ideas being proposed towards the end of the preparation time. Looking back, this was an unhelpful distraction but at the time demonstrated our enthusiasm and optimism.

Tajfel and Turner (1979 cited in Brown 1988) outlined that we assess our group's worth by comparing it with other groups. At one point the leader suggested we might fail for not responding to the question appropriately and described the group as incohesive. We were aware of other groups seeming ahead of us in their preparations. I feel we wasted valuable time here too, comparing ourselves to other groups rather than focusing on our own work. However we eventually developed a plan – to describe our process of getting on the PsychD course in the context of Hopson and Adam's transition cycle (1976).

Stage 3: Norming

As outlined by Moreland and Tenne (1982, cited in Brown 1988) the process of 'norming' within a group leads to self-concepts changing. Our group included diverse ages, genders, experiences and races. This enriched the perspectives we were able to take, though other individual differences can cause problems for clients in therapy. As an outcome of therapy we might hope that clients' self-concepts would change and new norms and interpretations would take hold. For me in retrospect it has been affirmed that

this is not a comfortable transition when supported by a group, so breaking long-standing patterns of thinking with time-limited support must be daunting.

I hoped therapy would run with common ground being found and improvements progressing smoothly, almost on 'autopilot' with solutions becoming obvious and positive gains being reinforced each week. This was optimistic but things have generally gone well. Accurate empathy, warmth and genuineness are regarded as backbones of therapeutic relationships (e.g. Truat and Carkuff 1967, cited in Sheldon 1995) that I hope I have demonstrated, but looking back to the PBL task they didn't all crystallize within our group until we actually had to perform the presentation.

Norming also means developing boundaries and defining (non) acceptable behaviour (Sherif and Sherif 1969 cited in Brown 1988). I found that this is an ongoing process in therapy where transparency is important. The chair was quite authoritarian though we didn't give this feedback. In contrast thus far when my clients have given constructive feedback I have coped and not interpreted it as hostility. On reflection for me, genuine, sensitive informed rapport emerged as the optimal precursor to change.

Stage 4: Performing

From examining the task in the light of subsequent clinical work, putting preparation into practice consolidated skills, learning and resources but required added trust. People may have been wary of their abilities at 'showtime'. Our group chose to use Hopson and Adam's (1976) Transition Cycle to explain our reactions to change in embarking on the course. This theory incorporated our sense of change being a wave-like process of continual adaptation and regression, rather than following linear, chronological stages. Though Tuckman and Jensen's (1976) model is linear I anticipate that we will regress to previous stages in our next PBL task. I wanted to entertain the audience and suggested we incorporate music to illustrate our points and the emotions that each stage described. We also dramatised our reactions, for example by joyously jumping in the 'excitement' phase to upbeat music. Our last run-through of the presentation took less time than was

stipulated and there was a high degree of synchronisation required for it to work - leaving us feeling quite anxious.

The day of the presentation was rather stressful. The first groups used video equipment. We had improvised with a roll of wallpaper and an outmoded tape deck. We felt we would be laughed at rather than with so we agreed to 'overact' so we wouldn't be taken seriously. One person was understandably reluctant to embarrass herself. However we committed ourselves, and the level of co-ordination seemed to entertain. The feedback was generally positive and two of our group members won acting awards from our peers.

The parallel I noticed with clinical work is in performing and thinking in the light of new knowledge, for example in behavioural experiments. The difference is that the PBL group was working towards one specific event. Our group was sufficiently confident and practised in communication to get onto the course so perhaps had fewer causes for concern. We had almost daily group support focused exclusively on this event whereas clients often have fortnightly 50 minute sessions covering a range of areas.

Lewin (1948) found that rewarding a group as a whole (e.g. by passing the assignment) is likely to lead to positive intragroup relationships. 'Interdependence of fate' (Lewin 1948) perhaps fostered our greater cohesion. This happened on the day - our group 'performed' but the preparation process hadn't always felt smooth. In the therapeutic relationship I believe that the reward is learning to feel or behave in ways that are less distressing. However clients may feel isolated and have to force themselves to change. Anxiety can then impact negatively on a number of levels and deteriorate into a vicious circle.

Reflections on the Group Process

Our group evolved in the way we communicate. Initially we all used the topic as a touchstone, perhaps trying to justify our course places, by making the most inspiring contribution. Now we problem-solve together rather than in competition. I feel we are all developing as therapists with the contingent increase in insight as to how people

(including ourselves) work and our optimal environments. We have now tentatively begun to share information about clinical difficulties. These disclosures should strengthen us in terms of solidarity but also in our own problem-solving, listening and communication skills. We have perhaps been initiated into making ourselves vulnerable for each other's benefit.

Learning Points

Personal

I enjoy writing and presenting, which I like to control but I recognise the value in relinquishing this autonomy. I need to find a balance between comfortably taking the lead and being prepared to compromise my ideas. This will also be useful in therapy whereby I can evolve unhelpful ideas without feeling deskilled. Timely and accurate feedback is something I also need to offer - this could augment the empathy and genuineness I should impart. I could also benefit from feeling more confident in therapy –though easier to say than do. I have been aware of appearing but not feeling confident and feel that this conflicts with both my professional identity and my need to be transparent and genuine.

For Others

Dealing with difficulties with the leader perhaps helpfully distracted us from other concerns and the presentation emerged relatively unscathed. However, as future PBL task leaders and contributors we have each agreed to focus on being democratic and diplomatic in achieving group goals rather than worrying about other groups or evaluation. We could also benefit from dedicating time to feedback and assuming success rather than failure. This optimism could improve trust and our willingness to contribute fully. Finally we could usefully improve our time management.

Final Reflection

When first contemplating this assignment I thought it might be difficult to compare a group task with the processes that occur in a dyad between individual therapist and client. However with further thinking as Allport (1962, cited in Brown 1988) outlined, the psychology of groups is the psychology of individuals – though the group may be somewhat of a gestalt entity there are parallel processes. I aim to apply this learning to a Cognitive Behavioural Therapy group for depression I shall be facilitating shortly. I feel that my clinical work has benefited from reflecting on the developmental stages inherent in our group's formation. This has been more informative than considering the PBL task in the light of clinical experience as I feel less expert as 'therapist' than I do as 'team member', having belonged to many groups before. A thread that emerged for me is that perhaps we assume roles and communicate differently unconsciously with clients and colleagues, which may not always be genuine or helpful.

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'Child Protection, Domestic Violence, Parenting and Learning Disabilities'

Problem – Based Learning Reflective Account

March 2007

Year 2

Problem Based Learning (PBL) Presentation Reflective Account – Child Protection, Domestic Violence, Parenting and Learning Disabilities

Introduction

Context

At the start of the second year on the Surrey PsychD course, each case discussion group (CDG) was asked to develop a presentation to facilitate problem-based learning (PBL) presentation to perform to the rest of the year, staff and visiting stakeholders. This was the second PBL presentation we had developed as a group. 3 2-hour sessions were dedicated to developing the presentation. Of our group, 6 of us were undertaking learning disability placements and one member had embarked upon a child placement. Our CDG had been allocated a psychodynamically oriented facilitator and we had experienced some interpersonal tensions over the preceding year when, but not essentially because, we were facilitated by a cognitive-behavioural therapist.

The Task

The situation was a complex one involving a wide professional network surrounding a family (the Strides) with parents described as ‘white English’, unable to read or write and living on state benefits. Their two young daughters had been living in foster care. Mr Stride had attended a school for children with special educational needs. Mrs Stride has a mild learning disability and had been the victim of domestic violence in a previous relationship (the children from which were removed) and it was a concern in the current marriage. The task given to the group was to undertake a risk assessment in the context of the local authority wishing to permanently adopt the children out.

Initial Thoughts

We had differing experience of the client group between us and were initially struck by the extent of the network surrounding the family and felt they would be justified in

feeling paranoid about the extent to which they were under surveillance. We discussed the possibility of this being something they have adjusted to. Hoping to start the development process I suggested the presentation could take the format of a courtroom battle whereby different 'sides' give their arguments and a decision is made. We discussed how we might utilise our time and agreed that we would work efficiently and pool our resources by reading separately and reporting back on different areas. In this sense the process became a little like a conveyer belt as we were now proficient at devising presentations. Research (eg. Lamm and Trommsdorff (1973) has shown that more ideas are generated when group members 'brainstorm' individually rather than together. I hoped this would mean we would work effectively as well as efficiently. We talked about what other groups would do and felt that the most memorable presentation from the first PBL task had made good use of video recording. We had also become aware during this PBL that use of audio-visual equipment was a factor we were assessed on. The previous presentation had not used any technology so we felt compelled to make a striking video. We also took the view that a presentation should be entertaining, though I will discuss the wisdom of this later in this account.

The Process of Developing the Presentation

Use of Time

In this particular incarnation, time was scarce and I felt we concentrated on some areas to the detriment of others. We spent lots of time recording a video pastiche. This left very little time to discuss and tessellate our parts of the script and no time to practice – the only rehearsal we had was on the morning of the presentation. Other than this occasion, we only met outside the prescribed CDG times once – to record the video. At the time I felt we had used far too much time talking about the generalities of the 'case' and not enough working on the practical aspects of how our presentation would look and sound. In retrospect however I feel the debates did add to the ease with which we were able to harmonise our differing views. Despite this we didn't have much time to make the script smooth and consistent, making for a rather raw performance.

Group Members' Contributions

We decided that we would divide up roles and each write our own section of the script. One previously quiet member of the team located and distributed several relevant articles and we each read and reported back on a small number of them. This seemed to work well with the ground we were able to cover expanding exponentially. There was some difficulty with sickness and I felt task distribution was a little *ad hoc* with one person undertaking the editing of the video rather than appearing in the presentation and one member having a small part as an audience member. I stepped in to be a programme presenter due to another member's sickness and felt quite anxious about having to neatly tie everything together on the spur of the moment though I acknowledged my desire to take control. I noted afterwards that I had also been concerned that if someone played their part 'behind the scenes' and was not obviously 'in' the presentation, it may cause problems. Afterwards I was unnerved to think that I had been more concerned about the group's mark than for repercussions for and the feelings of those who did not perform on the day.

Tension Within the Group

With our last group PBL presentation we had experienced tension with a member (who was the appointed 'leader') being controlling and making assumptions and unilateral decisions. I was concerned this would happen again but welcomed the opportunity to discuss the dynamics of the problem in the case discussion sessions of the CDG. This proved to be successful though more covert than I had anticipated, which may reflect the cognitive-behavioural leanings of the last year of CDG meetings. During this process there was little tension and I noted that the former leader offered (to no resistance) to play a less than pleasant, potentially ego-dystonic (for a psychologist) part and argue the case for the children being taken into care.

Performance on the Day

We were able to observe several presentations before ours was performed and decided to 'tweak' the final version and include a statement about our use of humour. This was to assert that we did not wish to trivialise the experiences of people in the situation we were describing. However, I eagerly launched into my introduction before the person had a chance to deliver this message and it was left unsaid.

Several groups used a similar format to ours – a TV news debate with trainees representing different professionals in the network surrounding the family. Our group used some caricatures of older people to represent the couple's parents (in-law) and some visual humour to depict middle-class foster parents. Unfortunately the audio-visual equipment wasn't producing sound so we had to show our much belaboured video on a smaller screen. The reaction from those present was positive with lots of laughter though with the backdrop of some serious presentations (including one with a court room battle being played out) and my missing out the statement about our intentions it felt a little inappropriate. I am unsure whether the statement was designed to protect us or our audience from the reality of the suffering the family would be experiencing if they hadn't been hypothetical. I am sure that had a real family been the subject of our presentation we would have behaved differently.

I must add that our presentation didn't humiliate or target any of the characters, but they were depicted in a light-hearted way. The topics of child protection and domestic violence were not treated as humorous - and a large part of our on-stage discussion was 'serious'. It was my view that we behaved in this way partly because the subject matter was potentially disturbing and partly because the weight we gave the process was greater than that given to the content as we wanted to entertain, and perhaps anticipated the need to write this account. In future I hope to ensure that difficult topics are treated with the appropriate gravity and that the desire to entertain others is second to the potential to inform them.

Communication Within the Group

I observed that our communication patterns had changed since our first PBL task which benefited our 'product'. Tschan (1995) found support for the hypothesis that good group co-ordination is possible where members adopt a common goal, develop a common understanding of the task, share and synthesis their opinions and give the process of achieving the task structure, ending with an evaluation. Much of this relies on good communication. By communicating widely through email and tuning our ideas in face-to-face meetings we went through these stages, if in a non-sequential way. Having relatively short face-to-face meetings meant we had to precis large amounts of information and were necessarily task-focused though the script produced was not 'fluid'.

Our ability to work more effectively together was, I feel, due to our future together as well as our past. Groenenboom *et al.* (2001) demonstrated support for the notion that group members efforts add to the group's product to the extent that members expect to work together again. We knew each other well from discussing personal concerns about clients, were dependent on each other to 'pass' the presentation as a component of the course and both of these processes would continue. There was then motivation for us to overcome the previous communication issues and we had invested in enjoying the process by making it entertaining.

Reflection

In terms of diversity our presentation did address the issues of class and the standards that one 'dominant' class applies to another – such as the fallacy that being able to read is a prerequisite for being able to parent adequately. I learned a great deal about the importance of the network around clients with learning disabilities. This vehicle for communication with clients holds difficulties for me given my background in adult mental health and the importance I personally place on the rights to information and considered, informed consent for any individual. I am still learning how different services and professions interpret these issues and can only conclude that the number of

possibilities is a product of the numbers of clinicians and presentations. Coupled with this, the conveyor-belt like methodology we used to put the presentation together was quite formulaic and were it not for the personal connections we have strengthened in the group since adopting a psychodynamic approach it could have seemed one-dimensional. It was a pity that only one group member is on a children and families placement as this meant her views were somewhat drowned out by our experiences. This could also have led to our content focusing on the needs of the parents and I noted that the person on a child placement opted to play a child in the video – perhaps to demonstrate her feelings. Our desire to use humour may be related to the precedent I have seen within some local day services to joke about serious client issues –such as about their romantic relationships or challenging behaviours. This can be done about, in front of or directly to clients and I experience witnessing it as shaming.

Several papers (eg. Lamm and Trommsdorff 1973 and Tschan 1995) include evaluation as an important stage in group processes. Since our presentation we have not revisited the performance and I feel it would be useful to feed back our feelings which I hope to do in a future CDG. Miller *et al.* (1978) found that people tend to feel more needed by a group when it has succeeded at a task, so emphasising failures (for example highlighting insensitivities around diversity) may affect our relatively newly found cohesion. This however is a topic for a CDG process account.

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'Working with Older Adults'

Problem-Based Learning Reflective Account

January 2008

Year 3

Problem Based Learning (PBL) Presentation Reflective Account – Working with Older Adults

The Task:

Our vignette involved a person with reported memory and self-care problems. The gentleman (Mr Khan), whose wife died 9 months ago, is of Pakistani origin. He has fallen out with his mosque since his wife died. Mr Khan's estranged daughter (who had adopted a more westernised lifestyle) contacted social services with her concerns. He has another daughter who is in an arranged marriage in Pakistan. Mr Khan moved to England 40 years ago with his wife. He is recently reported to have left pots boiling dry and his self-care has deteriorated. We were tasked with using this information to inform a presentation. Using such unstructured information is arguably a pre-requisite for a problem-based learning (PBL) task (Araz and Sungur 2007) and means the group has to make some assumptions and 'fill in the gaps'.

Our Group:

The composition of our group had changed since the last PBL task with one member opting to leave and a new member choosing to join us. We also had a new facilitator – someone who adopted a systemic approach. This contrasted with the former facilitator whose orientation was psychodynamic. The changes had left us reflecting on the dynamics within the group – something that was verbalised at our first case discussion group meeting. Teamwork would be an important factor in our success as a group; though we would not pass or fail the presentation we would rely on each other to maintain our self-confidence as trainees. Prince *et al.* (2005) reported findings that though students who used PBL methods reported many benefits, learning teamwork was not one of them – they hypothesise that this is because their participants did not need to rely on one-another for passing examinations. My interpretation is that though 'passing' or 'failing' is not an issue for us, a presentation is a highly visible task, incompetence or

disinterest would be very apparent and would impinge upon an individual's perceived position within the cohort. As such we would hopefully develop teamworking skills.

Initial Thoughts:

We had a brainstorming session and each identified our own perspectives. It was necessary for us to elaborate on the information provided, which I⁵ feel made it easier for us to fit the situation to our own ways of thinking. Areas that came up included: cultural expectations for carers, help-seeking, language barriers, cultural differences in gender roles, dementia 'blindness', cultural interpretations of age, dementia and mental health, westernisation of South Asian families, religious expectations, traditions regarding grief and bereavement and the accessibility and appropriateness of interventions for older people. This was a rich discussion with ideas about directions the presentation could take being many and varied. Having so many possibilities could have complicated the process, but as alluded to above, using unstructured problems creates possibilities for interpretation and creativity.

Some researchers (e.g. Colliver and Markwell 2007) have argued that PBL tasks do not confer any educational superiority upon courses that use them. Problems centre on the methodology used. Conversely, Prince *et al.* (2007) report both quantitative and qualitative benefits to medical students trained using PBL exercises. These students were more satisfied with their training than those trained without them. Cooke and Matarasso (2005) open their paper by stating that the 'future education of practitioners for the mental health arena needs to focus not only on the learning of practice-based skills but on thinking and problem-solving skills and theoretical frameworks for practice' (p243). They report a single case study of a student who was able to 'increase understanding and knowledge of a broad range of physical, social, political psychological and cultural issues' using PBL (p247). Prince *et al.* report no increase in general academic abilities, though improvements in psychosocial and interpersonal skills are as important.

⁵ I will use the first person in this account to facilitate reflexivity

Planning the Presentation:

We were aware that this presentation coincided with different stages of the major research project for us so opted to do as much work independently as possible then bring things together in a 'patchwork quilt' approach. We thought of many ideas and dismissed some for the labour intensiveness and others for insensitivity to the delicate balance of culture, family and religion that we identified in the vignette. We opted, through using empathy and assuming the perspectives of family members, to think how the situation might look from a variety of standpoints. Cooke and Matarasso (2005) suggest that such reflection 'affords the learner opportunities to explore experiences within a context and interpretative paradigm that facilitates new understandings' (p244).

We divided up the aforementioned topics amongst ourselves and I identified several papers on help seeking in South Asian communities. I summarised these and circulated them by email. At our next meeting I was surprised that no-one else had done the same and people seemed unclear about the direction we were taking. We revisited this and decided an outline for the presentation. We had recognised that there had been very little interactivity in previous presentations we had observed and felt that this gave us an opportunity to be different and to really engage the audience. I was pleased about this as I enjoy presenting and feel strongly that such occasions should be meaningful and entertaining. It also reassured me that others in the group were keen on making the presentation worthwhile as well as simple to prepare for. Reflecting on this point, I notice some judgementality on my part and have learned that things can be light as well as genuine.

We agreed the areas we would research again and met to pool our ideas. Unfortunately two group members were unwell so we could not yet run through the planned presentation. I was able to avoid feeling anxious about this by applying some well learned cognitive behavioural therapy techniques and disputing the grounds for my thoughts of certain failure!

It was interesting to note that we found it harder to find ways of injecting humour into this presentation, when our others have used it widely. I believe this is because of the ethnic diversity dimension characterising the description of the circumstances surrounding the 'problem'. This humour was replaced by a strong desire to understand the dilemmas faced by each member of the family at the heart of the vignette.

The Structure of the Presentation:

This was revised several times. We settled on asking the audience for their views on the information they would like a therapist (from another background) to know about their culture. We would then perform a sculpt with Mr Khan placing significant actors in this situation at the distance from himself he sees them at, and describing his reasoning. We would finally each give a brief account of our feelings about being placed in that particular distance. before reflecting on the circumstances in a case-discussion type meeting.

I was initially concerned that we were not giving enough to the process before coming to realise that creating a good presentation does not necessarily mean a gruelling development process.

The Presentation itself:

The presentations were to be held in the afternoon of a busy day. Though we had agreed to practice our presentation just before, one group member needed persuading that this was necessary. The rehearsal was complicated by making several decisions that had not been anticipated. I was somewhat concerned about how smoothly the event would run. I also worried that we would not have enough material to last the full 20 minutes. However I was wrong. We almost ran out of time and had to cut short our feedback section.

People engaged well in our 'audience participation' section and some interesting threads emerged. Everything proceeded in the correct order and felt quite seamless. It was

interesting to note that we had spent the morning in a session focussing on sculpting so our presentation seemed particularly well-timed. This was rewarding as I had worried that we had misunderstood what sculpting comprised. Formal and informal feedback afterwards suggested that our thoughts had been well received.

Diversity:

Diversity was a major theme in our presentation, as none of our group members shared the same ethnicity or religion as the family at the centre of debate. Some members had experience of living in other cultures and of the alienation this can lead to, so it was useful to hear their ideas about immigration. We had lots of 'folk knowledge' about the Muslim faith and I really appreciated the learning opportunity to discover the reality of its traditions and the various expectations placed upon different family members and genders in other cultures.

Reflections on the Process:

I have commented in previous accounts on the conveyor-belt like nature of the approach our group has taken towards PBL presentations. This incarnation of the PBL has however had great meaning for the individuals comprising our group. It was a chance to get to know one member and accept that another had wished to leave. It was also based on immigration an experience that we, for the most part, had to hypothesise about due to lack of personal experience. This tapped into my own ideas about cultural difference and left me with a greater range of concepts and feelings to draw on. The factual information was also quite helpful in widening my knowledge. I believe that this latter point has led to a greater emphasis in this account on the details of the planning and presenting process than in previous submissions. For example I have not listed the areas that have presented themselves in previous brainstorming sessions in so much detail before.

As this was our last problem-based learning task I feel it is important to consolidate our knowledge and acknowledge the benefits the PBL exercises have brought us. Though we

had not put lots of time into the project it was apparent that this was not through lack of interest, more because we each had other demands on our time. This ability to work quickly and effectively with minimal support and direction from each other will be useful when we come to work as newly qualified psychologists, without the solid support structures we currently enjoy and to which we have become accustomed.

Some people in our year have criticised the use of PBL tasks in training, but I feel it is an important mechanism by which we can bridge the gap between academic learning, and experiential learning in a safe way. In my research for this account I discovered several papers calling for 'real' scenarios to be used (e.g. Cooke and Matarasso 2005 and notably Chur-Hansen and Koopowitz 2004). The premise for this is that 'real cases' (to use a term I dislike) provide complexities and idiosyncrasies consistent with situations students are preparing themselves for (Prince et al. 2005). Though there are of course difficulties with ensuring informed consent and anonymity in this situation Chur-Hansen and Koopowitz point to the possibility that expressing trauma through writing can be of benefit to the individual client. They also remind us that in these days of service-user involvement and collaboration we may be obliged to work with real people as models rather than contrived, controlled composites of vignettes drawn from one individual's experience.

I would like to end my brief, but meaningful relationship with the PBL as an educational tool by adding my support for 'real' vignettes. I would like to state in the strongest terms however that this kind of user involvement should be at the level of partnership. The individual must be assured of their agency in the process and must feel respected and valued. By meeting these standards, the process of learning through merging theoretical and practical knowledge with psychosocial and interpersonal skills can benefit both learner and the client who can be recast as teacher, not 'subject'.

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'Case Discussion Group Process Account Year One'

Summary

September 2006

Year 1

Case Discussion Process Account Summary- Year One

I was unsure what to expect from the case discussion group having had negative experiences of group supervision in the past. We had chosen to meet in the early evening but soon found this left us tired and untalkative.

We were unsure of the reason for our group and frequently asked the facilitator (a CBT therapist). She did not explain but instead towards the end of the year asked us whether we were getting what we expected! Initially I found myself comparing our group to others, which perhaps did not allow our dynamics to develop.

Our group experienced many silences and I felt a powerful desire to fill these, at the same time exposing my lack of confidence about providing therapy. Other people shared cases on occasion and offered their thoughts on each other's situations, though the facilitator did not join in.

I felt there was a lack of group identification stemming from 'task disagreement' and 'interpersonal disagreement' (Pearson, Emsley and Amason 2002). However we held general discussions which left me uncertain about contributing from my own experience of being a service user, though not wishing to appear arrogant meant I did not share this in detail. I still felt I was taking up too much 'airtime' however. When others commented on cases I brought I found it difficult not to feel ignorant of dynamics I had not noticed.

I felt our case discussion group mirrored the team-trainee meeting, which suffered a similar confusion of identity. I discovered I had misconstrued the purpose of the group as group supervision. I learnt from it in terms of discovering the breadth and scope for individual differences within the clinical psychology profession. I feel this has been important despite a wish for us to disband being expressed.

'Case Discussion Group Process Account Two'

Summary

July 2007

Year 2

Case Discussion Group Process Account Summary - Year Two

Our first year of case discussion groups had left us sceptical about their value and purpose. As we were facilitated by a psychodynamically-oriented member of the course team I felt raising the issue that we had asked to dissolve our group and join others rather than continue to meet at an inconvenient time was prudent. The group returned to this issue with growing confidence over the year.

We had both similarities and differences but one member felt bullied by our reaction to comments they made in a bid to spark debate. Thus some similarities in feelings about their comments led this member to feel attacked. This type of interpersonal issue influenced subsequent discussions. The member who reported feeling bullied was offered the chance to leave, rendering the rest of the group uncertain of its identity and cohesion.

There was an inclination towards psychodynamic approaches in our membership and I wondered if our facilitator had been selected with the difficulties raised above in mind. I was unsure, given the content of our discussions whether the group provided ideas for clients we were working with, leads for case reports, or therapy. I was aware of using the group's therapeutic function. This left me feeling concerned I would seem incapable. We agreed to provide open and honest feedback and I received none to support this concern.

I was able to develop my reflective skills largely through observing others and relished the opportunity to discuss clients psychodynamically. I drew comparisons with common barriers to learning from reflective groups described by Platzer *et al.* (2000). I also identified some similarities between Bion's and our facilitator's approaches which assisted our group in its development to being competent second years.

Clinical Dossier

Placement Summaries

June 2008

Year 3

Summaries of Placements.

Adult Mental Health Placement: November 2005 – September 2006

Location: Sutton South Community Mental Health Team; South West London and St George's Mental Health NHS Trust.

Supervisor: Dr Peter James

In this placement I gained a broad experience that was representative of the type of work I would be doing as a qualified psychologist. As such I saw clients with many diagnoses including post traumatic stress disorder, schizophrenia, bipolar disorder, depression, obsessive-compulsive disorder, panic disorder with agoraphobia, health anxiety and organic problems. The approach I used was almost exclusively Cognitive Behavioural Therapy. I had a varied induction which included spending a shift on the inpatient ward linked to our service.

The beginning of my placement coincided with a time of change within the team. There was a threat of closure of the service linked to debates over the best way to manage caseloads and waiting lists. Given the uncertainty I chose to audit referrals from primary care for my Service Related Research Project. This was a sensitive topic as evidenced by the discussions and feedback that ensued from my presentation of my findings at the academic teaching session, attended by the clinical leads of the local CMHTs and psychiatrists in training. It is also notable that since I left this placement the consultant psychiatrist has sought my permission for her to have access to a copy of my project.

I developed a 10 week 'defeating depression' course based on the 'Mind over Mood' manual. This was supported by my supervisor who afterwards stated he had wanted me to get first hand experience of how difficult it is to run a group. My experience did not disappoint in this respect – attendance became too erratic to continue after 4 sessions.

A drawback of this placement was that I had limited opportunities to work with other professionals. I sought to remedy this in my next placement.

Learning Disabilities Placement: October 2006 – March 2007.

Wandsworth Community Team, The Joan Bicknell Centre. Wandsworth PCT.

Supervisor: Dr Britta Nagel

This placement was located within a community team for people with learning disabilities, located within Springfield University Hospital. I used psychodynamic, CBT and behavioural approaches in this placement. My experience was rich in working with varied personnel, including CPNs, speech and language therapists, physiotherapists, social workers, and occupational therapists. To model user involvement I was able to identify a client interested in joining a local consultation group who hoped to benefit from the social opportunities it provided. I also co-facilitated a social skills group with a speech and language therapist and a project worker from a local voluntary agency.

I also developed a score sheet for a screening tool that was being imported from another trust, and trained staff in its use. I jointly ran a group to help improve people's social skills, and was involved in developing a tool to assess suitability, screening potential participants and running the groups themselves. This was in conjunction with a speech and language therapist, a local support worker and an assistant psychologist.

I undertook more intensive psychometric assessments of people to establish whether they were eligible to receive services from a learning disabilities team. A significant achievement was attained by going through copious notes for a client (over 20 volumes) who had been referred several times. I was able to make some recommendations as to the most appropriate team to work with him and strategies for his family to implement.

The other clients I worked with had difficulties including impulsivity, bereavement, loneliness and relationship problems. I also worked with people with communication difficulties, dementia and challenging behaviour. I attended a supervision group facilitated by Valerie Sinason and left this placement reassured about my abilities to communicate accessibly.

Children and Families Placement: April 2007 – September 2007.

Merton Child and Adolescent Mental Health Services, South West London and St George's Mental Health NHS Trust.

Supervisors: Dr Georgina Bell and Dr Patricia Thornton

I used CBT, systemic and social learning principles in this placement. I was struck by the proportion of the team caseload with anxiety related problems. Therefore I developed a business case for an anxiety group for adolescents. I worked jointly with other psychologists with several clients to set this up and developed the agenda, the format and suitability criteria. This received positive feedback from the team and I presented my findings to them.

I provided a presentation on drugs and psychosis to the local Youth Offending Team. I also innovated, designed and produced an interactive board so that service users and carers could ask questions and request information that was not available before hand. On leaving the placement I established someone to take over keeping this updated.

I undertook four psychometric assessments and fed back information to children, parents and schools. This was across the age range of clients who were eligible to access the service.

I spent quite a lot of time in schools and worked with clients with obsessive compulsive disorder, anxiety, panic attacks, ADHD, anger management problems, autism and conduct problems. The ages of my clients ranged between 6 and 15 and I saw a few more female than male clients. I undertook observations in schools, both alone and shadowing another employee. I also worked with local children's services to access support for a family experiencing difficulties. This required undertaking local authority child protection training, which I attended.

Older Adults' Placement: October 2007 – March 2008

East Surrey Older Adults' Community Mental Health Team, Surrey and Borders Partnership NHS Trust

Supervisor: Ron Bracey

This placement was curtailed three weeks early due to problems within the service but I gained a substantial range of experiences.

I worked with more female clients than male, and with a variety of diagnoses. These included: PTSD, Anxiety, Depression, Alzheimer's Disease, Panic Attacks, Challenging Behaviour and Psychosis.

It was necessary for me to co-ordinate a response to a psychiatric emergency and I arranged an admission for a client who was feeling suicidal. Myself and another trainee on the same placement designed a presentation for the local Alzheimer's disease society. We also arranged for a shared drive to be available to the whole team to enable the sharing of information. We also devised an induction plan for new trainees and student nurses.

I worked largely within people's own homes and residential / nursing homes. I was also able to provide consultation and supervision to community psychiatric nurses within the team who were working with clients they were experiencing difficulty with.

Again I undertook psychometric assessments – one to screen for dementia and another to establish if there were any diagnoses co-morbid to one of Alzheimer's Disease.

I used largely CBT and schema focused approaches though there was some behavioural techniques needed for one particular client whom I enjoyed working with.

Specialist Placement: April 2008 – September 2008

**Chessington CMHT and Tolworth Early Intervention Services, South West London
and St Georges Mental Health NHS Trust**

Supervisor: Siobhan Woollett

I chose this placement to bridge between my interests in working in Adult Mental health and child services, and learning more systemic practice skills. I consolidated skills I had learned in previous placements and built confidence in seeing couples and families.

I saw clients for both individual and family work, being the lead therapist for one family (as part of a specialist clinic) and was in a reflecting team for several couples and other families.

Clients had a range of presentations, including depression, psychosis, anxiety and bipolar disorder. I co-facilitated two 'Understanding Psychosis' workshops for clients, alongside my supervisor and an assistant psychologist. I participated in two staff supervision / case reflection groups with staff and received group supervision from a family therapist. Team supervision also occurred regularly and comprised of a group facilitated by a therapist.

I undertook an audit of user involvement within the borough after liaising with local MIND services. I also gave a presentation to the psychological therapies department about my research.

I attended a BPS study day about dialogical approaches to working with individuals and families with psychosis.

'Cognitive Behavioural Therapy for a 50 year old Woman with Longstanding Panic Disorder with Agoraphobia'

Adult Mental Health Case Report One

Summary

May 2006

Year 1

**Case Report Summary: Cognitive Behavioural Therapy for a 50 year old Woman
with Longstanding Panic Disorder with Agoraphobia**

Reason for Referral

Carla was a 50 year old, white heterosexual Christian woman who had been almost unable to leave her house for 7 years. She self-medicated, using alcohol. The Alcohol Team had concluded that her agoraphobia and anxiety precluded their input. Carla could travel to familiar, local places when driven and could walk a short way with her daughter, though this took hours of preparation.

Presenting Problem

Carla had experienced extensive abuse and neglect throughout her childhood. She had had some experience of depression. Carla was in the process of divorcing her husband with whom she lived. Her children had special needs but lived independently and their wellbeing was essential to Carla's.

Initial Assessment of the Problem

We met at Carla's home. My assessment involved asking about recent attempts to go out (Vincelli *et al.* 2003). Due to literacy problems I did not administer any questionnaires. Instead Carla rated her own anxiety (on a scale of 0-100) each week. Initially, the thought of going out ranged between 75 and 100. Carla had had some negative experiences of therapy so I sought to be transparent.

Avoidance meant Carla could not describe her last panic attack and she was unsure of her exact fears. She reported generally wheezing and having a pounding heart. She had physical health problems linked to these symptoms making Clark's model of misattribution of symptoms insufficient.

Initial Formulation

Magee (1999) outlined that 'unpredictable and uncontrollable events leading to threatened or actual harm influence agoraphobia onset' (p351). Butler and Matthews (1983, cited in Craske and Pontillo 2001) posit that anxious individuals believe they are at greater risk of harm leading to biases in judgement of personal risk. My formulation reflected this in that Carla's childhood experiences led to core beliefs that people are a threat and the world is unsafe. Distress was minimised by remaining in a 'safe haven', drinking and seeking reassurance.

Action Plan

Carla planned her own goals for therapy:

1. To improve social skills and contacts
2. To not drink daily
3. To go out unaccompanied

Intervention

I chose to use Cognitive Behavioural Therapy (CBT) and used methods suggested by Craske and Pontillo (2001): Modifying threat-laden judgements and core beliefs; psychoeducation; identifying errors in judgement and collecting examples of errors and constructing more rational judgements. This was achieved using socratic questioning, guided exploration and the downward arrow technique as variously suggested by Vincelli *et al.* (2003) and Beck (1995).

We also used behavioural experiments (Hawton *et al.* 1985) to consolidate changes in thoughts, feelings and behaviours. 'Gradual exposure' (Butler in Hawton *et al.* 1985) began with imaginal exposure (Hawton *et al.* 1985). Carla then began attending a local drop-in. She could then access and name her fears. We discussed how her fear of attack

had developed. It emerged that Carla saw herself as a victim, exacerbated by her concerns at lacking social skills.

After Carla started attending her group regularly, to avoid extending her 'safe haven' to this new venue (Rachman 1998) we started varying homework tasks (Butler in Hawton *et al.* 1985). To manage experienced panic symptoms I provided psychoeducation and written information. I did not practice relaxation techniques with Carla as they stimulated distressing memories.

In the light of experience we modified Carla's beliefs that she had no social skills. We collaborated to identify and change her old rule ('everybody is hostile') into a more elaborate, flexible one. This process was aided by linking events to the model Carla and I had developed of her problems (the formulation).

Carla decided her alcohol intake was 'under control'. She 'never drank to get drunk' but to relax and distract herself. She initiated diluting her lager with non-alcoholic lager after we talked about the role it had in maintaining her problems.

In one session Carla disclosed that she had taken 20 painkillers some days previously. I took action to manage the risk and noted that this had happened at the end of treatment.

Outcome and Follow-up

The case report was written before our work finished but I evaluated our work using Carla's goals.

1. To improve social skills and contacts

Carla developed a friendship at the group and managed some difficult encounters. She reported that bringing down the 'brick wall' was surprisingly liberating.

2. To not drink daily

I referred Carla to the alcohol team as I prioritised her anxiety.

3. To be able to go out unaccompanied

After discovering the drop-in Carla attended almost every week. Her distress decreased by 43%, using her ratings. Carla found a way to tolerate others' proximity.

Reformulation

I ascertained that Carla's lack of early social experiences impacted on her view of her incompetence in social situations. I reformulated Carla's situation using Beck *et al.*'s step approach (1985). The initial formulation was retained and Carla's cognitions, elicited through behavioural experiments, were integrated.

Critical Evaluation of the Work

Recording anxiety ratings Carla provided subjectively was neither a scientific, reliable nor valid way of measuring change. It was contaminated by many factors – e.g. being rated in hindsight and one rating being taken per session rather than per outing.

It was difficult to proceed with some homework tasks as Carla did not like to write, in retrospect I felt I could have provided her with typed session notes.

Looking back at this piece of work reminded me of the despair I vicariously felt when hearing Carla's experiences. Her determination to succeed was inspiring and the

experience was valuable proof to me, a novice trainee, that talking therapies are potent. I felt reassured about my ability to establish rapport.

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*'Neuropsychological Assessment of Cognitive Function in a Client 11 years after an
Insulin Overdose'*

Adult Mental Health Case Report Two

Summary

September 2006

Year 1

Case Report Summary: Neuropsychological Assessment of Cognitive Function in a Client 11 years after an Insulin Overdose.

Reason for Referral

Claire has diabetes and took an overdose of insulin 11 years before we met following a period of depression. She has demonstrated difficulty in keeping appointments, seeming disorganised and forgetful. She was referred by her psychiatrist.

Presenting Problem

Claire reported forgetting to test her blood sugar level and take her medication - becoming hypoglycaemic and losing consciousness several times. Despite previous employment success she feels she now could not even cope with a job 'cleaning toilets'. She has recurrent depression. It was not possible to access an informant because of Claire's family situation.

Personal History

Claire reported not remembering much of her childhood. She gained good GCSE grades and left education aged 17. She had office based jobs requiring organisational skills - her last job was in 1989. She has divorced twice and has 4 children.

Literature Review

Insulin regulates the amount of glucose in the bloodstream. Overdose causes an abnormally low amount of sugar in the blood stream that means cells (in the brain and body) die as they rely on glucose to survive. This is termed 'hypoglycaemia' and can have physical, neurological and emotional consequences.

If glucose is not administered before the 'medullary' phase occurs, recovery may be delayed or incomplete (Cryer 1997). Victor and Ropper (2001) state that 'a severe and prolonged episode of hypoglycaemia may result in permanent impairment of intellectual

function' (p1183). Though some authors contest the existence of long term effects (Conway *et al.* 2001).

Various researchers have found evidence of alterations in blood flow to the frontal lobe and changes to the hippocampus in persons surviving hypoglycaemia (eg. Macleod *et al.* 1996 and Avery *et al.* 1984, both cited in Frier and Fisher 1999). The hippocampus is responsible for learning and implicated in memory (Benarroch *et al.* 1999). whereas the frontal lobe largely regulates executive function (Kopelman 2002).

Hypotheses

I hoped to discriminate between effects of Claire's depression and any possible neuropsychological impairment caused by her overdose, using her processing speed. I developed the following hypotheses:

1. Claire will have a neuropsychological profile commensurate with dysexecutive syndrome i.e. deficits in executive function compared with her premorbid intelligence quotient (IQ).
2. Claire's profile will be similar to profiles illustrating organic damage with impaired processing speed
3. Claire will show memory deficits consistent with damage to the hippocampus i.e. particularly in delayed and declarative memory

Rationale

I chose to administer a broad variety of tests (over 4 sessions totalling 10 hours) to most accurately delineate Claire's problems. These were:

1. The National Adult Reading Test (NART)

2. The Graded Naming Test
3. The Controlled Oral Word Association Test (COWA FAS)
4. The Trailmaking Test
5. The Rey-Osterreith Complex Figure
6. The Wechsler Adult Intelligence Scale (WAIS-III)
7. The Weschsler Memory Scale
8. The Behavioural Assessment of Dysexecutive Function (BADs)
9. The Hospital Anxiety and Depression Scale

These tests all had reasonable reliability and validity.

Presentation

Claire was pleasant though used some inappropriate jokes. She often cancelled at short notice or was late but reported being keen to pursue the assessment. Her strategies for approaching tasks often seemed haphazard.

Findings

Claire's premorbid IQ was estimated as 110 (high average). Her current IQ based on the WAIS-III was largely in the average range. Her memory gave scores at the bottom end of the average range. Though the Rey-Osterreith test was complicated by Claire's poor copy it suggested her visual memory and perhaps motor-co-ordination were impaired. Claire's executive function, as measured by the COWA FAS fell between the 25th and 50th percentile. Her processing speed (as measured by the Trailmaking test) was below cut off suggesting organic impairment. The BADs also suggested 'Borderline' executive functioning. Despite her concerns, Claire's word-finding as measured by the Graded Naming Test was average. Claire was found to be experiencing moderate anxiety and depression (according to the HADS). My observations suggested this did not contaminate the assessment.

Hypothesis 1. (Dysexecutive Syndrome)..

This was supported by the Trail-making Test. The extent of the impairment indicated by this test needs to be considered in the context of some research failing to support the authors' claims. However the BADS categorisation of 'borderline' problems also lends some support to the notion that there is some problem with executive function.

Hypothesis 2 (Impaired processing speed suggesting organic damage).

This was supported by the Trail-making test, and reservations about its accuracy were tempered by findings on the processing speed index of the WAIS-III.

Hypothesis 3 (Memory deficits consistent with hippocampal damage).

This was supported by the Rey-Osterrieth complex figure test, but not by the logical memory or graded naming tests.

Discussion

It could be concluded that there is some decline in cognitive functioning as detailed above – given visual memory and executive function results. This is slight but likely to be due to organic problems, rather than a functional problem given the profile outlined above.

Recommendations

I fed the results back to Claire - by letter then in person, and her team and made the following suggestions:

1. Presenting information to remember in more than one modality
2. Allow plenty of time for tasks involving processing information.

3. A system of repeated prompts, notes and alarms that fits her lifestyle.
4. Keep a single diary
5. Avoid having competing demands for Claire's time
6. 'Chunking' tasks and organising the day so items are linked
7. Planning each day in the morning to avoid multi-tasking

Critique

Not having access to an informant compromised my investigation. I was mindful that even assessments with demonstrated psychometric properties should not be accepted as objectively truthful. Though I was able to suggest the problem was likely to be organic, further physical investigations are required to explore this fully.

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'Psychodynamically Informed Extended Assessment of a 56 year old Woman with a Learning Disability and Problems with Overeating, Overspending and 'Inappropriate' Behaviour towards Men'

People with Learning Disabilities Case Report

Summary

March 2007

Year 2

Case Report Summary: Psychodynamically Informed Extended Assessment of a 56 year old Woman with a Learning Disability and Problems with Overeating, Overspending and 'Inappropriate' Behaviour towards Men

Referral of the Problem

Kate is a 56 year old white British woman with a significant learning disability. We have many similarities though age, educational and socio-economic contrasts exist. She was referred for 'overspending', 'overeating' and 'inappropriate advances' towards men.

Presenting Problem

Kate felt not having a relationship was her biggest problem. She had been 'suspended' from her day centre for repeated inappropriate invitations to male staff. She has health complaints complicated by her weight and previously accumulated debt but had inherited money after her mother's death.

Initial Assessment of the Problem

I experienced Kate as a larger lady, casually dressed and jovial.

Sources of Information used for the Assessment

In interview, Kate identified her problem as 'needing a man'. Her keyworker reported Kate would eat huge meals then nothing for several days though she did not purge. During Kate's review meeting, various staff located blame within Kate herself and seemed hostile.

Background History

Kate was referred for this work when her mother died. Her keyworker felt the current problems stemmed from a lack of structure. Kate's brother also has a learning disability but they 'do not get on'. She attended a school for 'delicate' children and has held two jobs. She exhibited a learnt response to emotional questions indicating communication impairments.

Kate had attended a day centre for many years. Her keyworker described her as 'bone idle'. Kate had money management problems but had other domestic skills. There was no evidence of mental health problems but she takes several forms of medication for her physical health complaints. Kate was bereaved of her Father, Mother and two pets within 7 years. She has had extensive support from her social worker and unsuccessfully saw a dietician.

Initial Investigations

Mini-PASADD

I hypothesised that some of Kate's 'symptoms' may be related to emergent depression. The mini-PASADD (Prosser *et al.* 1989) suggested that Kate currently has no mental health problems.

Initial Formulation

Kate's apparent indifference to others' feelings and perseverative advances may be neurological or linked to autistic traits such as inability to understand others' points of view and empathise appropriately, indicating that she *could not* pick up on others' cues. However I wished to acknowledge the role of Kate's feelings - perhaps she *would not* pick up on such cues.

The absence of a relationship and the staff's dismissiveness may impact negatively on Kate's self-regard. Her behaviours (e.g. overeating) may be a defence against this but lead to the pattern being reinforced (e.g. through weight gain). The numbing effect of food may prevent difficult feelings from being felt. Kate perhaps also wished to avoid the humiliation of the label 'learning disability' so acted in the opposite manner.

Initial Action Plan

I felt that an extended assessment of Kate's difficulties was warranted, to establish whether her ability to understand others' feelings, facial expressions and thinking was impaired. I also wished to explore methods for resolving Kate's problems – i.e. cognitive versus psychodynamic approaches. I also hoped to explore counter-transference and Kate's family's dynamics.

Extended Assessment

a). Interview with the Staff

Both male day centre staff members reported their praise being misinterpreted, one described feeling 'stalked'

b). Questionnaire Measures

The Attention Deficit Hyperactivity Disorder (ADHD) checklist discounted the possibility of ADHD. The Empathy Scale suggested that Kate's empathy is not impaired. The Eyes Test indicated Kate was highly suggestible and an advanced theory of mind task suggested a difficulty with receptive and expressive communication.

Fact Finding Sessions

I offered Kate individual sessions to explore her views and the formulation. In sessions, Kate often said she had no worries but conversely complained of being bored (leading to her spending money) and wanting a family. She demonstrated an ability to think symbolically. Information referring to mutual violence between Kate and her brother and to Kate accusing her brother of inappropriate behaviour became available at this point. Kate complained of not knowing what to say in sessions and attempted to disengage but continued attending after some persuasion.

Extended Formulation

Neither empathy problems nor autistic traits could explain Kate's behaviours. She had expressed that she felt desperately bored and lonely and missed family life. I was concerned that Kate had been the victim of physical and perhaps sexual abuse from her brother and I wondered about other family relationships. I felt Kate's projected wish to be nurtured and interpreted this as an indication that due to problems at home, Kate had not developed ways of providing a loving environment for herself. Day centre staff also felt Kate's anger which was returned to her.

Kate's choice of ideal partner, a member of staff suggests someone still in the fantasising stage of psychosexual development. Isolation was added to the formulation in terms of Kate's unfulfilled social and romantic life which was 'managed' and damaged by her 'symptoms'. A further dimension concerned the shame she may feel at her 'label' of learning disability (Roscoe, unpublished). I hypothesised she was portraying herself as bored as a defence against being overwhelmed by painful feelings. By spending money Kate was perhaps showing her power to the outside world and denying her impotence. Exaggerating her disability by passivity and indifference may be construed as a 'secondary handicap' (Sinason 1992).

Recommendations

Encouraging clarity, patience and tolerance may enable staff to develop an awareness of Kate's emotional life (Sheppard, in Hodges 2003). I feel she can work with symbolic concepts so psychodynamic work may be possible. However, her ambivalence about therapy suggests that the process and ethics of maintaining engagement may be problematic, particularly as she is often railroaded into activities chosen by others.

Critical Evaluation

I found it difficult to engage Kate, perhaps leaving it difficult explore what a romantic relationship would represent – intimacy, sexual gratification or 'entertainment'.

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*'Cognitive Behavioural Therapy with a 13 year old Young Woman with Obsessive
Compulsive Disorder'*

Children and Families Case Report

Summary

October 2007

Year 2

**Case Report Summary: Cognitive Behavioural Therapy with a 13 year old Young
Woman with Obsessive Compulsive Disorder**

Referral of the Problem

Sadie, a 13 year old young woman was referred by her GP as she felt compelled to touch certain objects, which was causing distress. Sadie's parents were divorced and she lived with her mother and brother though retained frequent contact with her father. There was a concern that Sadie may have Obsessive Compulsive Disorder (OCD).

Presenting Problem

Sadie described concerns about cleanliness and germs, orderliness and keeping things between school and home separate.

Initial Assessment of the Problem

The Assessment Process

Background History

Sadie felt she had had a 'delayed reaction' to her parents divorce. Her father had disclosed an affair to her before informing his wife (Dawn). Sadie's transition to secondary school was also difficult.

Developmental History

Sadie walked at 10 months and met other milestones such as talking appropriately. She did well when she went to nursery aged 2.

Initial Investigations

Questionnaire Measures:

I administered the Children's Yale-Brown Obsessive-Compulsive Scale (CY-BOCS). Sadie's global score was 29, indicating 'moderate - severe' OCD.

The Development of the Therapeutic Relationship

I chose to use the terms 'worries' and 'habits' to describe Sadie's obsessions and compulsions as these were less stigmatising. Sadie indicated she preferred this to the label 'OCD'

Being non-judgemental and reassuring Sadie that many other young people had similar problems, that she was not 'crazy' but recognising things were obviously hard for her, enabled her to relax and a good therapeutic relationship developed.

Initial Formulation

I felt that Sadie met the DSM-IV criteria for OCD. I felt that OCD was a way for anxiety, resulting from intense stress, to emerge. The intrusive thoughts that most people get leave the OCD sufferer feeling responsible for avoiding harm. Sadie had been given responsibility too great for her age when her father shared details of his affair with her.

Maintaining different hairstyles and clothes for school and home helped Sadie manage her anxiety and prevent bad feelings from being exchanged between the two but soon new 'worries' emerged and the neutralising behaviours became reinforcing of Sadie's problematic thoughts.

Action Plan

I hoped to help Sadie learn new ways of responding to her intrusive thoughts using behavioural experiments. I was aware of the value of exposure and response prevention (E/RP). However I was mindful of the need to tailor the treatment specifically to Sadie. In summary I hoped to desensitize Sadie to her anxiety cues by supporting her to not perform her compulsions.

Intervention

We met for 15 sessions. I drew on the work of March and Mulle (1998), Hawton *et al.* (1989), Hyman and Pedrick (2005), and Paul Stallard (2005).

We started by developing a hierarchy of Sadie's symptoms. She disclosed some 'mild' self harm early on and I conducted a risk assessment. Sadie also decided on an 'externalising' nickname for her symptoms.

We discussed a heated debate I had observed between Sadie and her mother. Apparently such exchanges were frequent. We explored the formulation, using this I introduced E/RP and the notion of 'bossing back' Sadie's worries (March and Mulle 1998). Further cognitive approaches included identifying problematic 'thinking traps'. In developing Sadie's behavioural experiments we explored the disadvantages of distraction and the benefits of progressing through the hierarchy in a planned, detailed and focused way. Initially we focused on cleaning behaviours

Sadie had said she wished to be less angry, We spent some time looking at anger management strategies. I described how things having to 'feel right' must lead to frustration and anger as they are quite uncertain and 'silly' behaviours don't remove the bad feelings. We drew a responsibility pie chart. Our behavioural experiments continued and I elicited the idea that moving on to a related group of problems would foster a sense

of achievement. Eventually, showering became easier and Sadie declared that she felt more in control of her bathroom-related problems.

Towards the end of our sessions, Sadie went on holiday. She predicted that her problems would increase in new surroundings so we spent time troubleshooting. Sadie suggested generalising 'showering' to new contexts by reducing time spent on this on holiday.

Reformulation of the Problem

The sessions we had had indicated that anger was a problem for Sadie, we collaborated to develop a formulation of the influence of anger on her symptoms. It led to frustration and more symptoms. We included the way she was able to harness her anger to resist her symptoms in a diagram that we drew together.

Outcome and Follow-up

I met with Sadie after a three-week absence for her annual holiday. Her mother reported that Sadie seemed more like her 'old self' and was happier than she had been for some time. She reported that she felt much more in control and that though she still had some small worries she knew how to defeat them. Her CY-BOCS score went down to 19 (mild – moderate OCD). The changes were centred around Sadie having intrusive thoughts but being more able to manage them. I offered her the opportunity to continue to see a colleague (who had conducted part of the initial assessment so was familiar to Sadie) as I was leaving the service. Sadie opted to discontinue and apply what she had learned to new problems that may emerge.

Critical Evaluation of the Work

I was inspired by Sadie's hard work and I felt that had I been subject to the stresses she had faced I would have found it difficult to cope. I was concerned that she had ended contact with the service as her CY-BOCS score still indicated 'moderate OCD'.

However this was discussed in supervision and I felt that the importance of Sadie feeling in control was paramount. I ensured she was aware she could re-engage with the service.

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*'A Behavioural Intervention for a 79-year-old man
Demonstrating Behaviour that Challenges Staff'*

Older Adults' Case Report

Summary

October 2007

Year 3

**Case Report Summary: A Behavioural Intervention for a 79-year-old man
Demonstrating Behaviour that Challenges Staff**

Referral of the Problem

Mr James Green is a 79-year-old white, British man who lives in a residential home

Presenting Problem

Mr Green was reported to open his bowels at inopportune moments daily, aggressively refusing staff's offers of assistance with personal care.

Initial Assessment of the Problem

This comprised of four interviews with Mr Green and others involved in his care.

Initial Interviews

The management team at the home, reported being at their 'wits' end' with him. Mr Green was said to laugh and enjoy their discomfort. He was thought to have sufficient sphincter strength to have voluntarily control over his bowels. It was stated he had a decreased ability to control urine output however. When Mr Green is confronted about this 'incontinence' he is described as being verbally abusive. Mr Green said everybody was nice. He reported not being aware of any big problems but described personal care as 'being changed like a baby'. His carer reported that often agreed to personal care when asked in his bedroom.

Background History

Mr Green was admitted to a nursing home after a fall. On regaining mobility he was transferred to a residential home.

A cursory screening for dementia using the Repeatable Battery for Assessment of Neurological Status (RBANS – Randolph 1998), tentatively concluded that there was some cognitive impairment indicating dementia but that this should be assessed thoroughly using the appropriate blood tests and scans.

Mr Green described his mother as ‘easygoing’ and his father as ‘too bloody Victorian’. To avoid being disciplined harshly, he had to stand up to his father – and he occasionally protected his brother. Mr Green left school at 14 and later flew bombers in the war. He proudly stated he always got his men home safely, but was interrogated on his return.

Mr Green’s son had moved abroad without any warning, His daughter-in-law was suspected of financially abusing him and his daughter rarely visited.

Initial Investigations

Antecedents – Behaviour – Consequences (ABC) Chart

This was used to get a detailed picture of individual instances of the ‘target’ behaviour, with the aim of establishing its function.

Development of the Therapeutic Relationship and Issues of Diversity

I anticipated that Mr Green would find it difficult to interact with me about this subject because of generational beliefs about helpseeking.

Risk

Despite verbal outbursts, there was no apparent risk of physical harm to others or to Mr Green himself.

Initial Formulation

I hypothesised that Mr Green found his environment restrictive and did not adapt well to his newfound lack of control. Staff asserting that his incontinence pads needed changing provided a way of taking back some control – by refusing he frustrated the staff, leaving them to feeling how he felt ('projection' - Lemma 2003).

Behavioural Intervention

I used the formulation to develop some strategies for containing and ameliorating Mr Green's difficulties by training the staff to support them and promote his independence. I met with four members of staff and followed the work up by contacting the new home on 4 occasions.

Before my training session, Mr Green was suddenly moved to a nursing home as the original management team convinced social services that his behaviour was uncontrollable.

Moniz-Cook et al. (1998) improved staff reporting of the management of behaviour that challenges using training techniques covering several areas. These were: the psychogenic and neurogenic underpinnings of behaviour that challenges, ways of communicating with the client, the dynamics of quality of life and the effects of the physical environment on it, and the importance of person centred planning. (p151). I incorporated these into an hour long training session.

I included some elements from the operant conditioning to prevent the 'need' for Mr Green to assert his control or make others feel as he felt.. In terms of maintaining Mr Green's independence I suggested he be given as much choice as possible – supported by NICE guidance (2006).

I provided a detailed and a summary version of my ideas using simplified language. I met with Mr Green before starting and gained his consent to talk to the staff, to 'let them know [his] likes and dislikes'.

Outcome

After 6 weeks Mr Green had had two 'accidents' (where faeces was found on his floor in the morning) but there had been no outbursts or refusals of personal care despite his unhappiness about being separated from his ladyfriend.

Reformulation

I had had a chance to process some of the information I had previously gathered, as such I included a cognitive-behavioural aspect to the formulation (adapted from Beck's 1985) representation.

Many of Mr Green's rules for living and coping strategies had been functional given his life experiences. Being strong and independent had protected him from his father and helped him keep his crew safe during the war, which had reinforced these behaviours. A core belief that he should be strong and in charge has resulted. Given his experience of protecting his brother, Mr Green displays a sense of duty towards those he perceives as suffering injustice, including himself. Cole, Scott and Skelton-Robinson (2000) found that staff mental wellbeing was correlated with the degree of support they perceive they have. Improving their working life and their reaction to Mr Green supported my decision to target the intervention at staff.

Critical Evaluation of the Work

My intervention with Mr Green was regrettably limited. Using a purely conditioning oriented formulation had been insufficient in describing Mr Green's presentation, and I

feel inclusion of the cognitive aspects in the reformulation greatly improved its explanatory power.

Though Mr Green and I spoke several times I did not get a sense that he had fully engaged with me, largely evidenced by a denial any problems though this may be predicted from the formulation.

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Research Dossier

*Audit of the Effectiveness of Changes to a System Designed to Improve the Processing
and Appropriateness of GP Referral Letters.*

Service Related Research Project

July 2006

Year 1

Abstract

Title:

Audit of the Effectiveness of Changes to a System Designed to Improve the Processing and Appropriateness of GP Referral Letters.

Objective:

To establish whether local GPs were making more appropriate referrals and trying treatments themselves before referring people on to secondary services as a result of systematising the process of accepting and providing feedback about referral letters within one CMHT.

Design:

A file audit of all referral letters received in the same two-month time period in 2005 and 2006. Letters were evaluated against a checklist developed from discussions with team members.

Setting:

A Community Mental Health Team with a caseload of 350. The team comprised of 3 psychiatrists (1 whole time equivalent, 2 part-time) 1 Senior House Officer, a Consultant Psychologist, a Trainee Clinical Psychologist, 2 Social Workers, 3 Community Psychiatric Nurses, 1 nursing student, a Team Manager (whose profession is nursing) and 2 Administrative staff.

Participants:

GP letters for the two time periods referred 107 potential clients – 69 were eligible.

Main Outcome Measures:

Frequencies in the form of percentages were calculated to establish differences between the two time periods.

Results:

Changes in referral rates between the two time periods were observed, though not in conjunction with more information being included

Conclusions:

The team has become more confident about not accepting all referrals and GPs seem to be being given less feedback now despite referring more clients who are 'Not taken on'. More feedback is required as GPs have not updated their methods in line with the Team.

Acknowledgements:

I would like to thank my host CMHT for their patience, the attendees of the academic meeting for their keenness to debate my findings, the consultant psychiatrist for advising me of the nature of the previous audit and the senior house officer with whom I share my office for making it all look so easy.

Introduction

The National Service Framework for Mental Health (Department of Health 1999) outlined provisions for people contacting primary services with a common mental health problem. They should 'have their mental health needs identified and addressed' and 'be offered effective treatments, including referral to specialist services for further assessment, treatment and care if they require it'. This document also outlined that 'high quality care' should be provided to 'persons with severe enduring mental illness'. The Community Mental Health Team Mental Health Policy implementation Guide (Department of Health 2002) in turn requires (among other functions) that Community Mental Health Teams (CMHTs) give advice to other professionals (particularly in primary care) on managing mental health problems. However 'service users' often criticise services' unresponsiveness – 28% of service users surveyed by Rethink (a mental health charity) reported being denied access to help they requested (Rethink 2002) despite previous contact. Targets and funding priorities mean that CMHTs have to spread themselves thinly (Gilbert *et al.* 2005), so deciding who to assess for treatment is a sensitive issue.

Letters from general practitioners (GPs) remain the primary method for referring clients to Community Mental Health Teams. Approximately 8 are received by this CMHT, from 7 local GP surgeries, each week. The CMHT has eligibility criteria regarding age, co-morbidity, location of client's home and GP surgery. Information about the reason for the referral is also needed. I observed in team meetings that parts of this information is often missing, leading to complications in making assessment decisions. This may reflect GPs' motivations to refer individuals. Morgan (1989) (cited in Sigel and Leiper (2004)) found GPs referred when their relationship with the patient deteriorated, rather than as a reflection of the severity of their symptoms. Sigel and Leiper (2004) suggest this may be due to the available time and expertise the GP has. According to treatment guidelines (eg. from the National Institute of Clinical Excellence (NICE)) many problems can be managed in primary care so some referrals may be pre-emptive.

Incompleteness and inappropriateness of referrals can lead to dangerous delays in providing care whilst more data are requested, or feedback outlining why a referral is

inappropriate is sent. This is a frequent cause of frustration for the CMHT who are left unable to make timely decisions. Involving secondary services can be stigmatising and so should be avoided where possible. Some specialist teams can accept direct GP referrals; their expertise is indicated in certain situations.

In 2003 an audit was carried out in this CMHT to evaluate an intervention based on liaising with GPs. This looked at referral rates before and after information giving but did not investigate the information letters themselves contained. Surprisingly it found the number of inappropriate referrals increased from 15% to 34% - perhaps resulting from raising awareness of the work of the CMHT.

One year ago the CMHT method for processing referrals became more systematic. Referrals are still discussed in weekly team meetings where the course of action for each referral is decided but the team are now more stringent and transparent about applying their criteria. Assessments are now not automatically offered to all. Giving GPs feedback per letter on missing information, or interventions they could instigate themselves (eg. those suggested by NICE guidelines) is now also systematic. Reassurance that the GP is already acting appropriately, information about the relevance of the referral and advice about alternative services are also frequently provided. I plan to assess the difference made by the team's new approach by comparing referrals received between January and February 2005 (Time A) and January and February 2006 (Time B).

Aims and Hypotheses.

I aim to explore differences in GP referral letters (both in quality and quantity). I hypothesised changes will have been effected by implementing a more consistent process for assessment decision-making. Specifically my aims were to:

1. Develop a checklist of information required for making decisions about referrals
2. Establish whether there is a difference in referral rate between the time periods before the system changed and one year later.
3. Determine whether there is a difference in the ratio of referrals in three categories ('Seen', 'Not taken on' and 'Written back' to) between the two time periods
4. Determine whether GPs were trying treatments more often after feedback
5. Establish whether GPs were writing more complete letters after gaps were highlighted

Based on these aims my contingent hypotheses were that:

1. There would be fewer referral letters in time B than time A
2. More referral letters would have resulted in being 'not taken on' in time B
3. More letters would be written back to in time A than time B
4. GPs would be trying treatments recommended by NICE more often in time B
5. GPs would more often include the information identified in the checklist developed in time B

Procedure

The CMHT comprises 3 psychiatrists, 1 senior house officer, a consultant clinical psychologist, a trainee clinical psychologist, 2 social workers, 3 community psychiatric nurses, 1 nursing student a team manager and 2 administrative staff. I regularly attended team meetings and observed decisions made about offering assessments to people referred. Based on these observations I devised a list of the information they contained. In discussion with my supervisor this was reduced to a checklist of 12 (Appendix A).

The next stage was to identify who had been referred in the two time periods by consulting the meeting record book. Using this as a guide I established the names and dates of each referral and used this list to find the original referral letter that had been received. Letters were relevant if they had been written by professionals located within primary care services. Thus letters from primary care nurse-practitioners were included. The letters were kept in the 'inappropriate referrals', and 'GP referral letters' files – both were checked thoroughly. Some letters were not present so I examined casenotes – of people still treated by the team and those who had been discharged and their files archived. People about whom letters were written were not directly contacted but were all aged between 17 and 65, 53.6% were male. Diagnoses are given in tables 4 and 5.

I checked each of these letters against the checklist (appendix A). These data were entered into an SPSS datasheet and frequencies of items in the criteria corresponding to the hypotheses above were calculated and compared. This process had determined that there were 107 referrals for both the time periods together. However only 69 were relevant as some letters could not be found and others had been referred by people within secondary services thus did not meet the criteria for eligibility.

I entered data into SPSS as to the action taken in response to each referral letter. Those whose outcome had been a letter written back to the referrer were identified and their names noted. Each of the letters written back was kept on the 'patient notes' folder within the Trust's computer system. These were individually inspected and recommendations made were noted. Again these data were entered into the SPSS datasheet and relevant frequencies were calculated.

Finally, being mindful of their relevance, I discussed my findings with service users in a local support group attended by users and carers.

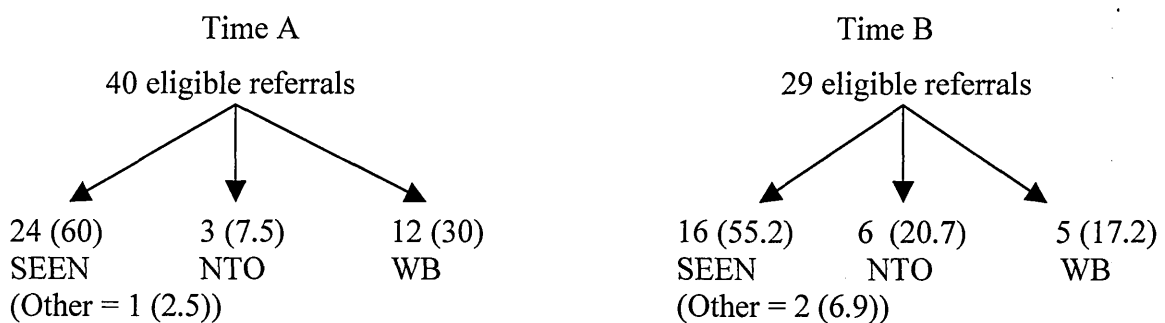
Analysis and Results

Hypothesis 1: There would be fewer referral letters in time B than time A

107 people were referred in the time periods specified – 61 in time A and 46 in time B. Of these, 9 letters (14.75%) in time A had been written by non-primary care referrers and 12 (19.67%) were not located in any of the files held by the team. For time B 11 (23.91%) referrals came from non primary care sources and 6 (14.63%) could not be found.

69 letters were eligible overall – 40 in time A and 29 in time B. These figures add up to more than 107 as some letters were both referred by sources other than primary care and were also not found. For time A this constituted 5 letters and 1 in time B. In absolute terms, hypothesis 1 was supported.

Hypothesis 2: More referral letters would have resulted in being ‘not taken on’ in time B
Figure 1. Frequency of referrals not taken on.



NTO = Not Taken On WB = Written Back Seen = Allocated for Assessment

Other = Outcomes such as referral on (e.g. to psychotherapy or alcohol services) and unresolved cases referred to the service director. Hypothesis 2 was not rejected.

Hypothesis 3 (More letters would be written back to in time A than time B)

Table 1: letters written back to referrer

Content of letter	Time A (%) (N=12)	Time B (%) (N=5)
Practicalities impeding arranging assessment appointment at this time	3 (25)	0 (0)
Eliminate physical health problems first	3 (25)	2 (40)
Get more information about mental health symptoms	2 (16.7)	0 (0)
Reassure GP treatment tried is appropriate	1 (8.3)	0 (0)
Recommend trial of SSRI	2 (16.7)	1 (20)
Client inappropriate	1 (8.3)	1 (20)
Treat in primary care	0 (0)	1 (20)

Hypothesis 3 was supported.

Hypothesis 4: GPs would be trying treatments before referral more often in time B

Table 2: Treatments tried before referring (time A)

	Seen (%) n = 24	Not Taken On (%) n = 3	Written Back (%) n = 12	Other (%) n=1	Total (%) n=40
Treatment Tried?	Y= 17 (70.8)	Y= 2 (66.7)	Y= 7 (58.3)	Y=0 (0)	Y= 26 (65)
Dose Given?	Y = 13 (54.2)	Y = 2 (66.7)	Y = 5 (41.7)	Y=0 (0)	Y= 20 (50)
Response to Treatment Tried Given?	Y= 6 (25)	Y= 1 (33.3)	Y= 1 (8.3)	Y=0 (0)	Y= 8 (20)

Table 3: Treatments tried before referring (Time B)

	Seen (%) n = 16	Not Taken On (%) n = 6	Written Back (%) N = 5	Other (%) n=2	Total (%) n=29
Treatment Tried?	Y= 11 (68.8)	Y= 4 (66.7)	Y= 3 (60)	Y=1 (50)	Y = 18 (62)
Dose Given?	Y = 5 (31.3)	Y = 2 (33.3)	Y = 2 (40)	Y = 0 (0)	Y = 9 (31)
Response to Treatment Tried Given?	Y= 4 (25)	Y=3 (50)	Y= 0 (0)	Y=0 (0)	Y= 7 (24.1)

Hypothesis 4 was narrowly rejected – the margin of 3% is negligible especially given the small sample size.

Hypothesis 5: GPs would more often include the information identified in the checklist in time B

Table 4: Content of letters (Time A)

		Seen (%) N = 24	Not Taken On(%) n = 3	Written Back (%) n = 12	Other(%) n=1	Total (%) n=40
Gender Given?*		Y=24 (100)	Y=3 (100)	Y=12 (100)	Y=1 (100)	Y=40 (100)
Gender		M=12 (50)	M= 2 (66.7)	M=5 (41.7)	M=1 (100)	M = 20 (50)
Diagnosis Given?*		Y= 20 (83.3)	Y= 2 (66.7)	Y= 10 (83.3)	Y=1 (100)	Y= 33 ()
Diagnosis	Schizo- phrenia	3 (12.5)	1 (33.3)	1 (8.3)	0 (0)	5 (12.5)
	Dep- ression	11 (45.8)	0 (0)	5 (41.7)	0 (0)	16 (40)
	Bipolar Disorder	1 (4.2)	0 (0)	(0) (0)	0 (0)	1 (2.5)
	Anxiety	2 (8.30)	1 (33.3)	1 (8.3)	0 (0)	4 (10)
	Other	7(29.4)	1 (33.3)	5 (41.7)	1 (100)	14 (35)
Symptoms Described?*		Y= 22 (91.7)	Y= 3 (100)	Y= 9 (75)	Y=1 (100)	Y = 35 (87.5)
Duration Given?*		Y= 10 (41.7)	Y= 1 (33.3)	Y= 3 (25)	Y=0 (0)	Y = 14 (35)
History Given?*		Y= 14 (58.3)	Y= 2 (66.7)	Y= 9 (75)	Y= 0(0)	Y= 25 (62.5)
Urgent?*		Y= 6 (25)	Y=0 (0)	Y= 2 (16.7)	Y=0(0)	Y= 8 (20)
(Non/) Urgency Justified?*		Y= 6 (25)	Y= 0 (0)	Y= 4 (33.3)	Y=0 (0)	Y =10 (25)

Table 5: Content of letters (Time B)

		Seen (%) n = 16	Not Taken On (%) n = 6	Written Back (%) n = 5	Other(%) n=2	Total (%) n = 29
Gender Given?*		Y=16 (100)	Y=6 (100)	Y=5 (100)	Y=2 (100)	Y=29 (100)
Gender		M= 11 (68.8)	M= 3 (50)	M= 1 (20)	M=2 (100)	M = 17 (58.6)
Diagnosis Given?*		Y= 9 (56.3)	Y= 5 (83.3)	Y= 5 (100)	Y=2 (100)	Y = 21 (72.4)
Diagnosis	Schizo- phrenia,	1 (6.3)	2 (33.3)	0 (0)	0 (0)	3 (10.3)
	Dep- ression	1 (31.3)	1 (16.7)	3 (60)	1 (50)	9 (31)
	Bipolar Disorder	0 (0)	1 (16.7)	0 (0)	0 (0)	1 (3.4)
	Anxiety	3 (18.8)	0 (0)	1 (20)	0 (0)	4 (13.8)
	Other	0 (0)	1 (33.3)	2 (20)	0 (0)	3 (10.3)
Symptoms Described?*		Y= 13 (81.3)	Y= 6 (100)	Y= 5 (100)	Y=1 (50)	Y=25 (86.2)
Duration Given?*		Y= 2 (12.5)	Y= 2 (33.3)	Y= 1 (20)	Y=1 (50)	Y=6 (20.7)
History Given?*		Y= 11 (68.8)	Y= 2 (33.3)	Y= 5 (100)	Y= 2 (100)	Y=20 (69)
Urgent?*		Y= 3 (18.8)	Y= 1 (16.7)	Y= 1 (20)	Y=0 (0)	Y = 5 (17.2)
(Non/) Urgency Justified?*		Y= 2 (12.5)	Y= 0 (0)	Y= 1 (20)	Y=0 (0)	Y=3 (10.3)

In all of the 7 relevant categories (marked by *) there was a decrease in reporting, though some differences were minimal. Hypothesis 5 was rejected.

Summary of Hypotheses

1. Supported (40 letters vs 29)
2. Supported (3 NTO vs 6)
3. Supported (12 letters vs 5)
4. Rejected (65% vs 62%)
5. Rejected (all 7 categories were reported less often in time B)

Discussion

In terms of hypotheses 1 and 2, analyses suggest that the systematisation of the referral and feedback decision system implemented in the CMHT has preceded a decrease in referrals, a drop in assessments and an increase in people not taken on (diagram 1). A decrease in the numbers of letters written back occurred alongside these changes (table 1). Consistent with hypothesis 3, letters written back contain more suggestions about investigating or containing the problem within primary care in time period A. The feedback given in letters has included fewer recommendations about treatments to try before referring in time B yet fewer treatments are being attempted before referral (tables 2 and 3) - the opposite of what was predicted by hypothesis 4. It is impossible to say whether feedback is needed less often after the changes to the system as referral letters in time period B contain less information than they did in time period A (tables 4 and 5).

It seems the CMHT took its educative duties seriously at the time of the change in assessment decisions. The hypothesis was that fewer letters would be needed in time B as GPs would learn which data they needed to include and would infer eligibility criteria from these letters. However the decrease in response letters may be premature – I recommend that even when a referral is accepted for assessment, a letter going to the GP to confirm this should highlight missing data.

20% of letters in time A were described as ‘urgent’ by the GP with 17.2% being described that way in time B. In time B one of these was ‘Not taken on’ without further correspondence being entered into – perhaps reflecting the team’s increased confidence in making assessment decisions.

Booton and Collerton (1998) (cited in Sigel and Leiper (2004)) acknowledge that accurately identifying mental health problems in primary care can be difficult as they present at an earlier stage. I hypothesise that with more people being turned away when specific problems are described GPs may be referring problems they are less sure of and do not wish to speculate about. Tables 2 and 3 suggest that GPs have been attempting treatment themselves marginally less frequently in time B (by 3%) – this tentatively

supports the notion though further study is needed. Feedback may have decreased GPs confidence in some areas whilst empowering them to not refer everybody on (leading to the decrease in referrals). In contrast it is noteworthy that GPs gave slightly more information about responses to treatments tried in time B, though many still do not report this.

The extent to which symptoms are described has remained relatively static despite feedback – though 13.8% of GPs in time B still did not include this information. Overall the amount of information included in time B decreased from time A, contradicting hypothesis 5. An interpretation may be that by having access to less information about the referral, the CMHT is not convinced of the eligibility of the individual for secondary care. This does imply that including the information identified on the checklist is a formula for a referral being accepted – the important consideration being the nature not just the presence of information.

In conjunction with letters going to GPs to highlight missing information, I recommend that a referral pro-forma is designed that indicates all of the information required so that GPs are made more aware of eligibility criteria. I feel this would be more beneficial than liaising with GPs directly – partly due to time and resources issues but also because the previous audit found that interpersonal interaction with GPs led to an increase in referrals. This phenomenon has also been found by other researchers (eg. Murphy, James and Lloyd 2002). Sigel and Leiper (2004) also found that GPs views of psychological problems were influenced by contact they had with psychologists – again in this case leading to greater referral rates. None of the surgeries included have a psychologist directly available. I recommend investigating funding for the primary care trust to employ a psychologist to facilitate the filtering of referrals to secondary care.

Talking to service users about my findings was interesting in that the group seemed unsurprised. Service users generally felt that they were aware when they felt they needed help and that they would, on the whole, not object to secondary services being involved. However the group I spoke to was comprised of people who had been ‘in the system’ for

some years – probably long enough for this form of stigmatisation to become manageable.

Evaluation

There were several limitations to this study. Firstly generalising from a file audit is usually inadvisable. Given this relatively small sample size – with some conditions yielding only 3 participant letters - demonstrating any meaningful change is particularly inconclusive. Also the time period chosen was difficult in that the period immediately post-Christmas is likely to be unrepresentative of ‘typical’ referral rates. I feel that to confirm and explore findings, a much greater sample size is needed.

There was a large number of letters that were not eligible – either as they were not from primary care sources or the letters were not retrievable and designated ‘lost’. Calculations show that 34.42% of letters were missing in time A and 38.54% in time B. Though this proportion was slightly larger for time B than time A this difference amounts to only 4% - which would not fully account for the effects observed. I recommend that copies of referral letters are kept in one place as regular audits of referral data may aid policy decisions. This audit was conducted in a service in a state of flux – with uncertainty about funding, senior management are currently refining CMHT policy on assessment processes.

The extent to which it was possible to involve service users in this research was limited by the nature of the file audit in general. I decided to feed back to local service users so that my audit was in some way connected to the people the team serves. Though they offered political rather than practical suggestions it was useful in challenging some ‘accepted’ knowledge (eg. people prefer not to be referred to secondary services).

Summary of Recommendations:

1. Letters to feed back when information is missing
2. Develop a referral pro-forma for GPs

3. Investigate the option of psychologists being employed in primary care
4. Repeat the study with a greater sample size
5. Keep copies of letters in one place

I fed back my findings to the service at an academic meeting (Appendix B). Much debate was generated as with service configuration imminent the issue of caseload both for teams and individuals was highly contentious.

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Appendix A

Checklist for Referral Letters

GP Letter Checklist

Number	Criterion	Description of information captured
1	GP surgery	Name of surgery
2	Name of GP	Individual referrer's name
3	Date seen by GP	Information included? - Yes / No
4	Diagnosis Given	Yes / No and nature
5	Symptoms Described	Yes / No and nature
6	Duration of current problems	Yes /No and length of time
7	History of the individual referred	Information given? Yes / No
8	Whom the letter was directed to	eg. Psychiatrist / psychologist / team
9	Treatments tried?	Yes / No and nature
10	Dose of medication given?	Yes / No and size
11	Urgency	Was the letter designated 'urgent'? Yes / No
12	Urgency justified	Did the GP give a reason why the letter was / was not urgent? Yes / No

Appendix B

Feedback Presentation

N.B This contains preliminary data as it was given before all data had been analysed.
The team were fed back to separately

Audit of the Primary Care – CMHT interface

Trainee Clinical Psychologist
Sutton South CMHT

Why?

- SRRP is a course requirement
- Anecdotes about referrals not meeting 'caseness' requirements
- GP referral letters remain most common access point to secondary services

Policy – NSF standard 2

Any service user who contacts their primary care mental health team should:

- Have their mental health needs identified and addressed
- Be offered effective treatments, including referral to specialist services for further assessment, treatment and care if they require it'

MHPIG – Community Mental Health Teams

- 'Everyone who is referred should usually be assessed'
- It is 'Not possible to limit assessments to severely mentally ill – GP skills vary and advice on the management of common disorders and also confirmation that people are not suffering from psychiatric disorder is part of the service'

MHPIG – Community Mental Health Teams

Functions required include:

- 'Giving advice on the management of mental health problems by other professionals – in particular advice to primary care and a triage function enabling appropriate referral'

NICE Guidelines

- Exist for most 'common' disorders
- Included GPs in their development
- Contain treatment guidelines and good practice points (e.g. schizophrenia guidelines)
- ?Implementation

Frequency of referrals

Sigel and Leiper (2004)

- GPs refer <10% of mental health problems they detect to specialist services

GPs accuracy

Goldberg and Huxley (1992)

- GPs with a stronger bias toward assessing a problem as psychiatric diagnose more people as mentally ill, but these diagnoses are not necessarily more accurate

GP decision-making

■ Nandy *et al.* (2001)

- Decisions to refer patients often occurred when GPs were experiencing negative emotions about patients such as frustration and irritation.

Difficulties for GPs

■ Booton and Collerton (1998)

- Defining problems is more difficult in primary care because the patient is presenting earlier with symptoms that are less well developed

GP decision-making

■ King, Bailey and Newton (1994)

Developed an analytic framework incorporating factors such as GP's judgement of self harm risk, relieving burden of care and GP-patient relationship

Aims

- To establish whether fewer people were being taken on after 'caseness' decisions became more systematic and GPs were given feedback
- To assess differences in referral rates between January and February 2005 and January and February 2006

'Caseness'

- Age
- Primary Diagnosis
- Geographical location

Also...

- Stage of disorder
- Reaction to treatments tried so far

Method

- Developing a checklist of features of good quality referral letter
- Eliciting names and decisions of people referred in time A and B from records
- File search – 'inappropriate letters' file, GP referral letters file and casenotes
- Data entered onto SPSS and frequencies calculated

Checklist

■ GP / Surgery	■ Dose (s) given
■ Date seen	■ Response to treatment
■ Directed to	■ Urgency
■ Diagnosis	■ Risk Justified?
■ Symptoms described?	■ Action taken (seen, not taken on, written back to)
■ Duration of symptoms	■ Appropriateness of referral - helicopter view
■ History	■ Discharged?
■ Treatment(s) tried so far	

Results

- 107 referrals made all told
- 61 in time A
- 46 in time B
- 68 referrals from Primary care
- 21 letters missing
- Sample = 37 people in time A
31 people in time B

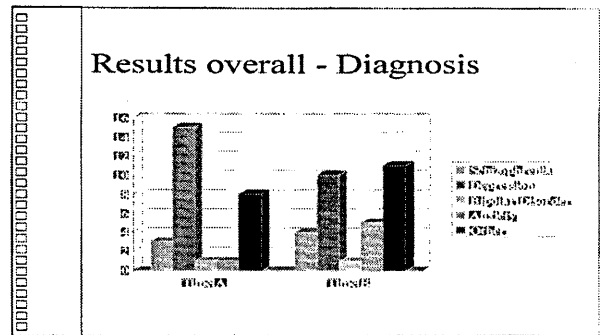
Results

<p>Time A 2005</p> <p>37</p> <p>28 seen (75.7%) 9 NTO (24.3%)</p>	<p>Time B 2006</p> <p>31</p> <p>19 seen (61.3%) 12 NTO (38.7%)</p>
--	---

Results - Overall

	Time A (%) N=37	Time B (%) N=31
Gender	M = 18 (48.6)	M = 20 (64.5)
Diagnosis Given?	Y=30 (81.1)	Y=22(71.0)
Symptoms Described?	Y=31(83.8)	Y=26 (83.9)
Treatment(s) tried?	Y=25 (67.6)	Y=21 (67.8)

Results - Overall		
	Time A (%) N = 37	Time B (%) N=31
Reaction to treatment described?	Y=7 (18.9)	Y = 9 (29.0)
Urgent?	Y = 7 (18.9)	Y = 7 (22.6)
Urgency Justified?	Y = 9 (24.3)	Y = 5 (16.1)



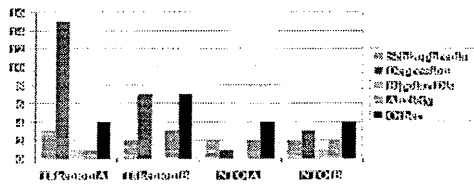
Results – People taken on		
	Time A (%) N = 28	Time B (%) N = 19
Gender	M = 12 (42.9)	M = 12 (63.2)
Diagnosis given?	Y = 25 (83.9)	Y = 14 (73.7)
Symptoms described?	Y = 23 (82.1)	Y = 16 (84.2)

Results – people taken on		
	Time A (%) N = 28	Time B (%) N = 19
Treatment tried?	Y = 22 (78.6)	Y = 14 (73.7)
Reaction to treatment?	Y = 6 (21.4)	Y = 5 (26.3)
Urgent?	Y = 7 (25)	Y = 5 (26.3)
Urgency Justified?	Y = 9 (67.9)	Y = 4 (21.1)

Results – people not taken on		
	Time A (%) N = 9	Time B (%) N = 12
Gender	M = 6 (66.7)	M = 6 (50)
Diagnosis given?	Y = 5 (55.6)	Y = 8 (66.7)
Symptoms described?	Y = 8 (88.9)	Y = 10 (83.3)

Results – people not taken on		
	Time A (%) N = 9	Time B (%) N = 12
Treatment tried?	Y = 3 (33.3)	Y = 8 (66.7)
Reaction to treatment?	Y = 1 (11.1)	Y = 4 (33.3)
Urgent?	Y = 0 (0)	Y = 2 (16.7)
Urgency Justified?	Y = 0 (0)	Y = 1 (8.3)

Results - Diagnosis



Summary

- Fewer people were referred in time B
- A greater proportion were not taken on in time B
- A slightly greater proportion of referrals in time B were 'urgent' for both TO and NTO (no-one NTO in A was 'urgent')
- Diagnosis was given less often for people not taken on for both time A and B

Conclusions

- Greater confidence in making the decision not to assess in time
- GPs AND CMHT more selective in time B
- Much has remained the same (eg. describing symptoms and trying treatments)
- Described more responses to treatments in time B
- Still important parts of information missing eg. Diagnosis, symptoms, response to treatment so far

Drawbacks

- Audit – not explanatory or generalisable
- Small N
- Time of year not necessarily representative
- Compare with in service referrals?
- Short time period not necessarily capturing rereferrals

Next steps

- Greater 'N' – consider March 2005 and 2006
- Consult with service users – 2/3 turned down when asked for care
- Look at referrals written back to
- Meeting NICE guidelines? SSRI trials recommended
- Consult with GPs?

Beware!

'Closer working with primary care is associated with a sharp increase in referrals to community mental health services'

Murphy, James and Lloyd (2002)

References

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Sigel, P. and Lejper, R. (2004) *'GP Views of the management and referral of psychological problems'* *Psychology and Psychotherapy: Theory, Research and Practice* (2004) 77, pp279 - 295

Appendix C

Feedback Letter from Team Consultant

27th June 2006

To
Trainee clinical psychologist

Re: G.P. Referral Audit and Presentation 4th May 2006

Dear

Thank you very much for doing this audit for our team and presenting it at the academic programme. It raised some interesting points as well as a fascinating discussion!

Yours truly,

Service User Involvement in Developing NICE Guidelines:
Bridging the Evidence – Experience Gap

Major Research Project

October 2008

Year 3

Word count: 19947 excluding references and appendices

Abstract

Rationale:

Patient involvement is increasingly required by the Department of Health (e.g. DoH 2001). Mental health guidelines from the National Institute of Clinical Excellence are developed by multi-disciplinary guideline development groups (GDGs) and determine treatment advice for people with mental health needs (service users), enshrining their involvement in developing guidelines. However given the nature of the contribution service users can make (being lay rather than 'professional' members) the process of involvement requires GDGs to incorporate different types of evidence (research-based and experience-based). The present study explored service users' perceptions of their involvement in GDG meetings.

Participants:

Ten service users were interviewed, representing nine GDGs. Exactly half were male.

Methodology:

Grounded Theory was used to analyse data from transcripts as little research exists in this area and it prescribes robust techniques for analysing data.

Results and Discussion:

A metaphor of GDGs resembling a group of experts designing a machine emerged. Collaboration between service users and professionals is possible but requires energy. User experience and research evidence can complement each other and together form more comprehensive guidelines. Experience is construed as an analytical tool rather than a form of data. Notions of research evidence being widely generalisable and user experience being idiosyncratic are challenged. Deliberative justice is often seen to apply (where the process of deciding recommendations is reasonable, transparent and includes an appropriate breadth of ingredients) even where specific recommendations are contrary to individual service users' own preferences. Recommendations for GDGs are made.

Acknowledgements

I owe a great amount to Dr Rachel Perkins for inspiring and supporting me in my career – without her my vocation might have passed me by. I would like to acknowledge the staff and members of the charity ‘Rethink’ – whose support and access to opportunities have helped me to develop the confidence and experience that enabled me to embark on and complete this doctoral training programme. I am also indebted to the staff at Acer Ward, Huntingdon for helping me find my way through my ‘dark year of the soul’.

I couldn’t have undertaken this research without the support of the staff at the College Research Unit, most notably Cathy Pettinari (my field supervisor) whose kind encouragement and support made it all look so easy. I also have to thank my participants for giving me a glimpse of the complex world of NICE guideline development in such a candid and thoughtful way. The people I have worked with on placement, both clients and staff have similarly inspired and moved me. Dr Mark Hayward, my university supervisor is personally responsible for my application to the Surrey PsychD course and has consistently helped me to stretch my horizons and take on new challenges. Dr Dora Brown has accommodated my absent-mindedness with a sense of humour that has brought some of the more detailed philosophical concepts I have been grappling with to life.

My friends have not complained about my being distracted by psychology research over the last year. This particularly applies to my very good friend Muriel, the mother of my Godchild, Tom, both of whom whose resilience and curiosity have reminded me of the wonder of learning. I would like to thank my parents – Sue and Denis and my brother, Jamie for having faith in me even when I didn’t.

Finally I must send a heartfelt thank you to my life partner, Dom. He has reacted to my varying research and portfolio-related frustrations with a steadfast calm that is truly amazing, and also provided unsurpassable technical support, often at the drop of a hat. Without him I would be lost.

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'It doesn't matter what you do to service users as long as they like it'

Anon

Service User Involvement in Developing NICE Guidelines:

Bridging the Evidence – Experience Gap

1. Introduction

This introduction will outline reasons for choosing this area of study and introduce the research and theory that already exists on the subject. Pertinent concepts will be defined and the rationale for the research design and question will be described.

1. 1. Reasons for Selecting this Topic

Throughout training as a clinical psychologist I¹ have been fascinated by the changing shape of my chosen profession. Influences as diverse as government policy and research evidence are being used to affect how clinical psychologists work. This and experience of being a service user has led me to carefully consider the ways clinical psychology has been ‘standardised’ across the National Health Service (NHS). For example ‘Agenda for Change’ has impacted on the roles psychologists take, and the increasing dominance of Cognitive Behavioural Therapy (CBT) changes the treatment people with mental health problems (service users²) are likely to be offered. The prevalence of treatments is greatly determined by guidance developed by the National Institute of Clinical and Health Excellence (NICE). This guidance is developed by groups of experts who assess available research evidence and prioritise cost-effective treatments for specific disorders. Patients (here service users) are included in this process. The Department of Health (DoH) has made clear the NHS’ obligation to involve patients in service development (DoH 2000, 2001). This is likely to have an impact upon the practice of clinical psychologists, who develop close relationships with service users, in both contributing and adhering to guidelines.

¹ I will use the first person in this section; to facilitate the reflexivity required to state my motivations for conducting this research.

² Though discord over the appropriate terminology is acknowledged, the term ‘service user’ will be used throughout this study in keeping with the majority of literature on ‘service user’ involvement, some written by service users themselves.

1.2. Functions of the National Institute for Clinical and Health Excellence (NICE)

The National Institute for Clinical Excellence (NICE) was launched in 1999 and its role further amplified as The National Institute for Clinical and Health Excellence (NICE) in 2004 following the Government's white paper 'Choosing Health: Making Healthy Choices Easier'. It is an independent organisation producing guidance on public health, health technologies and clinical practice. It holds responsibility for developing treatment guidelines for clinicians working in England and Wales on a variety of disorders or concerns. NICE is responsible for the development of treatment guidelines that partly govern the practice of many British psychologists. Guidelines are evidence-based with the results of relevant studies being reviewed by guideline development groups (GDGs) made up of relevant professionals, carers and patients (service users) alongside methodologists. GDG members are recruited from services and stakeholders, communicating through meetings or confidential electronic mail. They sift through evidence (e.g. research studies) and develop recommendations based on their judgements of it.

1.2.1. How Guidelines for the Treatment of Mental Health Problems are Developed

Evidence on specific disorders is frequently collated into disorder specific guidelines for ease of reference and implementation. Guidelines have been described as 'systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances' (Field and Lohr 1992 p2). They are aimed at making healthcare 'less variable, more reliable and efficient' (Moreira 2005 p1975). Moreira also reports that guidelines are necessarily evidence-based and rely on a multidisciplinary group of professionals and a methodologically focused research team. Guidelines also utilise judgment; Moreira *et al.* (2006 p1199) report that this means guidelines have been described as 'evidence biased' rather than 'evidence based'. Fitzgerald *et al.* (2003) in a study of the diffusion of innovative interventions assert that 'credible evidence' is not easily defined, implying that it is a subjective phenomenon, as opposed to the objectivity that might be expected from such a scientific endeavour.

Shekelle *et al.* (1999) described the optimal methodology of developing treatment guidelines as involving five steps:

1. Defining the scope – the specific areas the guideline will address
2. Recruiting to and running guideline development groups
3. Conducting systematic reviews of evidence which the aforementioned groups will evaluate
4. Translating the above evaluations into a set of recommendations
5. Subjecting the guidelines to review by stakeholders

This is an abbreviated version of the methodology, based on the experiences of the authors in developing guidelines in the UK and America. Stakeholders are professional, private and charitable organisations whose practice, membership or sphere of interest might affect or be affected by guidelines being developed. These bodies (e.g. pharmaceutical companies or charities) are asked to submit evidence they feel is relevant and are able to comment on guidelines in the review stage. Shekelle *et al.* (1999) add that recruiting group members requires identifying all of the professions whose practice would be informed by the guidelines and all those who have 'legitimate reasons for having input in the process' (p 593). Service users, psychiatrists and psychologists would arguably be among the most eligible candidates for mental health-related guidelines.

1.2.2. Other Methods of Developing Consensus

Several methods for reaching group consensus exist. The Delphi Method (Dalkey and Helmer 1963) involves several stages conducted remotely (group members do not meet). Initially individuals list their views and ideas qualitatively. Questionnaires containing likert scale items based on these data (and sometimes further qualitative data) are developed and completed by group members in subsequent rounds. Consensus is reached statistically (based on Murphy *et al.* 1998). Criticisms include the disadvantages of not having face-to-face contact, individuals becoming disinterested when questions are not

framed appropriately, cost, and the adverse impact of anonymity (leading to carelessness) (Rudy 1996).

The Nominal Group Technique (NGT) (Delbecq and Van de Ven 1971) starts with individuals privately recording their views on the topic. A facilitator then describes one idea from each person in turn before the whole group until all ideas are shared. Participants then vote, or first privately list their revised judgements before voting - ongoing aggregation leads to a group judgement (based on Murphy et al. 1998). Disadvantages of the NGT include the time taken to discuss the range of issues GDGs are concerned with may be prohibitive or anonymity meaning opinions do not change. NICE methodology might combine the benefits of face-to-face discussion; GDG members all being encouraged to have a say (for example via standing agenda item for 'service user and carer views'); and a mechanism for keeping to time. Transparency may be useful given people state opinions in public but may mean some views are not expressed.

1.2.3. The Influence of NICE Guidelines

Eccles *et al.* (1996) report that guidelines are valid if adhering to them results in the health gains and financial costs they predicted. They add that guideline validity relies on three variables: the composition of the guideline development group and its processes, the ways in which evidence is identified and assessed; and the guideline creation methodology. The resultant guidance describes processes and methods that services and individual clinicians are advised to follow. Guidance on different clinical presentations (e.g. self-harming) is developed through NICE, published then disseminated to relevant services, though implementation and evaluation are often locally driven. Recommendations address service, psychological, pharmacological, nursing, and other interventions. McArdle (2007) argues however that NICE guidance on depression in children and young people 'risks distorting practice' (p66) because of methodological limitations potentially common to all NICE guideline development processes. These will be discussed later.

A public or patient version of each guideline is published which informs patients which treatments they can expect. Despite the abovementioned drawbacks, adherence to NICE guidelines is a frequent subject of NHS audit, and has been utilised by clinical governance departments as a yardstick of success. Also, referral to some NHS services is only possible after other NICE recommendations have been exhausted. The power guidelines have in restricting access to treatments and services necessitates high standards and scrutiny from the consumer, the service user. Most health-related professions, including psychology, have their work at least partially determined by NICE guidance on the disorders or populations they treat, making guidelines of national importance. The recommendations that each guideline development group has determined to be key priorities for implementation are audited and as such, recommendations made by NICE clearly and directly affect the treatments service users are offered, which psychologists often provide. Psychologists are therefore heavily influenced by NICE guidelines and are rightly included in their development for mental health related disorders alongside service users.

1.3. Service User Involvement

The English service user movement can be traced back to the 'Alleged Lunatics' Friends Society' born in 1845 (Frese and Walker Davis 1997). Stickley (2006) adds that more recently the closure of institutions and the problems associated with care in the community in the 1980s influenced the inception of patients' councils and advocacy services. From 15 service user groups existing in the mid-1980s there was a massive growth to over 700 in 2006 (Rose *et al.* 2006). Stickley reports that user involvement is usually construed as ascending the power hierarchy inherent in mental health systems. The 'ladder of involvement' model (Tew *et al.* 2004) is one illustration of this hierarchy, with the apex being 'partnership working'. Stickley calls instead for emancipation, with service users taking power on their own terms rather than perpetuating the dominant discourse (the medical model). By this, he questions involvement and instead describes service users as providing a service for those previously seen as the service providers.

Carers are also valued stakeholders in mental health services, though their roles are quite different. Goodwin and Happell's research (2006) supports the view held by many activists and academics that service user and carer views are not synonymous, and that in some cases (e.g. the need for confidentiality contrasting with the need to know about a loved one's situation) they can be in direct conflict. Rose *et al.* (2006) report that though some research is being developed by service users, there is a paucity of carer-led research, making it difficult to extrapolate their true perspectives. Whilst the need for further carer-led research is emphasised, this study focuses on service users as to explore both effectively would require two studies.

1.4. Professionals' Views on User Involvement in Research, Guideline Development and Service Development.

Involvement, whether user- or carer- depends on others. Campbell (2001) suggests that the attitudes of mental health professionals are frequently regarded as a significant barrier to effective service user involvement. Summers (2003) reported that psychiatrists have been identified as the most opposed to user involvement by three studies: Barker *et al.* (1997), Peck and Barker (1997) and Barnes and Wistow (1994).

Moreira *et al.* (2006) report that patient members of groups they studied made 'limited contributions' to the development process, despite 'no lack of opportunity' (p1206). Entwistle *et al.* (1998) reported that non-expert involvement in research had not been universally accepted, despite its prevalence and the extent to which it is required by the Department of Health. Objections include notions that people who get involved are not representative of the majority of people with the disorder under investigation; that other professionals are capable of representing client views appropriately; that they make no difference to the product of the process they are involved in and that they are unlikely to be objective. Wensing and Elwyn (2003) add that client decisions about priorities in healthcare tend to be based on an individual experience rather than a general view. It may be argued that these points are also true of many service providers (Entwistle *et al.* 1998). Entwistle *et al.* also suggest that 'consumers' are often glad to be involved in a

decision-making process with other professionals even if the outcome is not what they had sought.

Van Wersch and Eccles (2001) describe a 'realistic perception that attempts at involvement [of service users in guidelines] have been driven by political correctness...' (p11). In a study conducted to explore models of user involvement, they found that service users 'involved' in a guideline development process made few contributions. Areas they did contribute to were described as 'circumscribed' (tending to be in the areas of patient education and self-help) and their input was rarely incorporated in the product of the development process. They were also described as having difficulties with technical language and 'their understanding of the use of scientific evidence in order to contribute to a more cost-effective health care remained unclear' (p12). Two points may be noted – firstly the contributions consumers made to these guideline development processes were measured quantitatively (i.e. the number of sentences spoken throughout the meetings). Secondly the authors concede that with training provided by workshops, patients could understand the technical components of the development process and subsequently contribute in a 'relevant' manner. Van Wersch and Eccles describe this as a 'relatively resource intensive' endeavour however (p13). A further concession was that an advocate recruited to one of the groups was able to speak up among the 'professionals' within the group, had experience of discussions with health care professionals and possessed an understanding of terminology. It is not beyond the realms of possibility that many service users might possess similar experience and confidence.

Soffe *et al.* (2004) found clinical psychologists' views of involving service users in service development were generally positive. This may be expected (or hoped for) given the impetus for clinical psychologists to work with service users as 'equal partners' (British Psychological Society (BPS) 2001 p2). Psychologists may be in a position to involve service users as partners both in service development and in partnership within the therapeutic relationship. Soffe *et al.* referred to the extent to which clinical psychology training courses train psychologists to work with self-help, advocacy and user-led organisations, those services that are arguably those most likely to highlight

service user needs and generate a catalyst for action. They also describe the variation in types of involvement in training. Individual differences along with these inconsistencies in exposure to service user involvement are likely to produce psychologists with varied opportunities, inclination and motivation to involve, act on or elicit the views of service users.

1.5. User Involvement in NICE Guidelines to Date

The NICE Patient Involvement Unit (which recruits service users to NICE GDGs) conducted a survey in 2004 of some 55 members of 20 GDGs (Jarrett 2004). This found that though patient members as well as group chairs gave positive feedback about patient involvement, some problems were evident. These concerned the provision of information; training and support; involvement in and/or dissatisfaction with the area the guideline attempted to address (the scope); the organisation and conduct of meetings, patient research skills and access to information on other patient views. This survey included views from members of guidelines outside the field of mental health.

Optimising service user involvement in developing NICE guidelines would seem to be a valuable enterprise. Many agencies, including guideline developers and organisations representing service users, have asserted this (Kelson 2001). Moreira *et al.* (2006) report that though studies investigating the influence of status and professional roles of people comprising GDGs have found these characteristics to be important, research has not yet indicated how guideline production itself might change. Given the strategic position psychologists have adopted on partnership working (see below), they may be well placed to improve the involvement of often-disadvantaged service users. The ways all health professions work are now heavily determined by reliance on sharing evidence of what works.

1.6. Evidence-Based Practice

At the same time as the NHS was moving towards being ‘consumer-driven’ (further involving service users), evidence-based practice (incorporating evidence-based medicine for medical professionals – including psychiatrists) gathered momentum and became the dominant model (Moreira 2005). Evidence based approaches generally require that the highest quality evidence from clinical trials is incorporated with clinical expertise to identify those interventions that are proven to be most effective (Spring *et al.* 2005). These include pharmacological and psychological interventions. Evidence-based approaches aim to determine what is best for the individual being treated and how best to manage health-related resources (Culpepper and Gilbert 1999). Almost a decade ago, Culpepper and Gilbert recognised that evidence that respects and involves the client’s own values and decisions might greatly advance the process of making treatment-based decisions.

Spring *et al.* (2005) outline arguments against the use of evidence based practice by clinicians – suggesting that it devalues the therapist–client relationship, that it undermines clinical judgement; that recommendations ration services, that people already use the approaches suggested and that it is often based on research that is irrelevant to the daily decisions clinicians face. Culpepper and Gilbert (1999) also raise the spectre of areas where evidence does not exist. Roth (2006) rallies against the ways in which CBT has assumed dominance in the eyes of powerful commentators (e.g. Lord Layard) because of the ways in which it is evaluated. Roth balances the good CBT undoubtedly does for many with the risk of unrealistic targets being set and therapists being constrained as to the modes of therapy they can practice.

The process with which evidence is gathered is also subject to debate; randomised controlled trials (RCTs, where participants are randomly assigned to experimental conditions and treatments are standardised (Spring *et al.* 2005)) are deemed the most robust way of assessing the value of a treatment (Dyer and Joseph 2006). However, RCTs use populations that clinicians are unlikely to come across in their practice as they utilise

efficacy studies (of the effect) rather than effectiveness studies (of the treatment overall) (Spring *et al.* 2005). Clients accessing services rarely have one presenting problem with few complicating factors.

1.6.1. Psychologists and Evidence-Based Practice

Psychologists have their own evidence-based approach to practice. Beck (1976) developed CBT – perhaps the most widely researched area of psychological intervention – as an evidence-based approach. Clinical psychology training (after the Boulder model), currently aims to produce ‘reflective scientist-practitioners’ (Tarrier 2006). This translates as developing clinicians with high-level skills in assessing ‘scientific’ psychological evidence and applying it to individuals’ clinical problems. The ‘reflective’ aspect complements this and refers to having the ability to step back from the therapeutic relationship and assess the influence of factors such as diversity and power in a way that impacts upon future encounters. Tarrier (2006) suggests that a psychologist’s judgement can be usefully complemented by such reflection, suggesting understanding and respecting individuality improves clinical psychology practice.

The ‘formulation’ is used to inform an appropriate intervention plan (Sperry 2005, Tarrier 2006) and is a working model of an individual’s situation. This is often a description of the interplay between factors precipitating, triggering, characterising and maintaining an individual’s distress. Formulations tailored to an individual’s circumstances have been found to improve treatment outcomes, for example at six-month follow-up after a behaviour therapy intervention (Jacobson *et al.* 1989). However the usefulness of formulations themselves is hard to objectively verify (Tarrier 2006) though the interventions they inform have shown some success. Formulating may be considered an art rather than a science. The efficacy of psychological therapies, based on formulations shows that psychologists’ practice of applying data elicited from groups to individuals is frequently successful. To support this statement, talking treatments are often sought by service users seeking to alleviate their distress. (‘We Need to Talk’ (Bird

2006)). Formulation is individualistic, though Kuyken *et al.* (2005) assert that even ‘two different formulations of the same case could both be valid’ (p1198).

1.7. The Medical Model: A Dominant Discourse?

Psychologists are not the only profession whose business it is to ‘treat’ mental health problems. Psychiatrists are the embodiment of the medical profession in the mental health team. The medical model applies to general practitioners and psychiatrists – those with arguably most influence in the NHS. Parker (2007) states that psychiatrists ‘are accorded more status than the psychologist’ (p24) and that psychology ‘tries to award itself higher status...to ally itself with medicine’ (p23). Psychiatrists, by virtue of their training, traditionally employ the medical model to diagnose and treat mental health problems (Halleck 1976). Boyle (2006) outlines that the medical model (in the context of mental ill health), and suggests that ‘unusual’ experiences (such as hearing voices) can be explained in the same way as physical health problems – using the same biological ‘disease’ related terminology and processes.

Freeth (2007) states that the medical model assumes a logical positivist position. This is reflected in the critical, dogmatic assumption that the medical model is ‘crude and taxonomic’ (Tarrier 2006 p 2). Kanfer and Saslow (1965) describe psychiatric diagnosis as being constrained by ‘issues of precision, consistency, reliability and validity’ (p 529) – though these criticisms may also be made of the formulation. Tarrier (2006 p4) suggests that for psychologists, the ‘disease concept is in danger of replacement by ‘equally diffuse’ concepts such as dysfunctional assumptions. As an extension of the medical model, Whitley and Crawford (2005 p106) describe the extent to which psychiatry is monopolised by quantitative as opposed to qualitative research. They assert that many psychiatrists view qualitative research as ‘fundamentally esoteric, if not inferior’. This may impact on views of the relative value of more experiential, qualitative data and hence influence their treatment decisions.

1.8. The Identification of Appropriate Research Evidence

For NICE guidelines, identifying relevant material involves systematic searches of the Cochrane library for articles reporting relevant studies, which are then assessed for the robustness of their methodology. Initially, NICE adopted a system listing categories of evidence from Type I (at least one good systematic review, including at least one RCT) to Type V (expert opinion, including the opinion of service users and carers). However with evidence coming from multiple sources this taxonomy is no longer used. Instead the strength of recommendations is communicated by the language used to describe the intervention advised. Service users are recruited to help decide these relative strengths.

1.9. Decision-Making Processes in GDGs

Psychologists may aid the process of developing treatment guidelines in tandem with service users, but GDG members come from a range of professions relevant to the particular condition under review. This could make the decision-making process still more elaborate. The expert members of GDGs assess and interpret the evidence provided by literature searches, and form recommendations based on their combined opinion. There are many factors influencing the development of guidelines, their complexity and the need for interpreting evidence (or agreeing an approach where there is no existing evidence (Shekelle *et al.* 1999)) makes the process more than the aggregation of knowledge (Raine *et al.* 2004). Though evidence may exist on a facet of a clinical 'problem' (it does not always), its interpretation is not an automatic process. Raine *et al.* found that clinical guideline recommendations developed by General Practitioners (GPs) and mental health practitioners directly agreed with the evidence in only 51% of 192 scenarios.

Guidelines do not emerge from or into a vacuum. Economic concerns, often the scourge of public healthcare services, may be predicted to be an important factor in the shape of the final version of a treatment guideline. However Raine *et al.* found that they did not make an important difference, though it was not clear whether the guidelines developed

by this group were to be used on a national or local level or whether they were only for the purposes of the study. Many studies of the processes determining clinical recommendations have been undertaken. For example, Moreira *et al.* (2006) identified 4 domains influencing interactive reasoning following the qualitative analysis of transcripts of 21 guideline development group meetings. These were:

Science: The standard of the evidence they were assessing and how their recommendations might withstand the scrutiny of academics and researchers.

Practice: The transformation from recommendation to clinical practice and how practitioners may view the statements developed.

Politics: The extent to which external commentators (e.g. the media, the voluntary sector) may perceive the recommendation as critical or withholding.

Process: Negotiating the process of decision-making itself (this was linked to ‘boundary setting’; evidenced in the interplay of different domains).

Accountability to the external world had already been identified by Moreira (2005) as a powerful incentive. This can be readily observed as a motivating factor for psychologists in their discussion of ‘impact factors’ of published research (e.g. Liuch 2005). Different group members may demonstrate varying levels of reliance on each of these domains (Moreira 2005).

1.10. The Influence of Sources of Evidence on Decision-making

Some types of evidence (notably service user and carer experience) may be valued differently by various group members given differences in training. This suggests that the types of knowledge involved (science versus experience) could play an important part in the way guideline development groups deliberate. The ways in which different types of knowledge or evidence are developed highlights an important difference; that people with

personal experience of mental ill health *understand* their journeys. In contrast professionals endeavour to *explain* mental illness through various models, theories and treatments (Lawrence 2004). The way these types of knowledge are integrated to produce influential treatment guidelines provides the basis for the present research. As highlighted above, psychologists occupy a unique position by virtue of their training which focuses on taking nomothetic data (that applying to groups, in this case possibly experimental populations) and applying it idiographically (to the individual) – by developing a unique formulation for each client seen.

1.11. Ranking and Power in the Multidisciplinary GDG

Researchers are unequivocal about power differentials existing between mental health professionals and service users (e.g. Chamberlin and Rogers 1990). Freeth (2007) argues that the medical model (demonstrated by psychiatrists and medical professionals) locates the professional as the agent to define the individual's experiences, with pathology placed within the client. Moreira (2005) introduced his study of guideline development processes by referring to the possibility of disputes between different members '...mirroring wider demarcation between...groups of health professionals and along lay/professional divides. This strategy would also partially assume that the outcome of these controversies would be derived along the power differentials that exist along the aforementioned demarcations' (p1977). The conclusion that service users, psychologists and psychiatrists may have differing influences on guideline development processes should not be assumed but remains an interesting question.

1.12. The Social Psychology of GDGs

Power, status and group numbers can affect intergroup relating (Sachdev and Bourhis 1991). Power can relate to the ability to reward or coerce another group or the level of expertise the powerful group commands. Mental health professionals, with the function of admitting patients to hospital involuntarily are likely to be viewed as 'powerful' from a service user point of view. Tajfel and Turner (1986) defined status as the educational

achievement, occupational status, wealth and other 'valued dimensions of power' (Sachdev and Bourhis 1991 p3). As such their extensive training and the extent to which GDG members represent the cutting edge of expertise in their relevant fields may accord them relatively higher status.

. 1.13. The Nature of Evidence

The content and positions adopted by different members of a GDG may be communicated by the types of information they utilise. A key feature of NICE guidance, as mentioned above is that they are evidence-based, seemingly an unambiguous term. However, Rose *et al.* (2006) report that 'the epistemological status of evidence is now often disputed' and that 'for some authors universal knowledge is a myth as all knowledge is situated and contingent. If this were accepted then it would reduce the knowledge / power relation between practitioners and policy makers and users and carers' (quotations p112). So service users and mental health professionals may find it difficult to integrate their knowledge or positions, and possibly see themselves as separate despite being urged to work together. Power and social comparisons may therefore influence the process of 'objectively' making important decisions (Coleman and Harding 2004).

Rose *et al.* imply that experience may be constructed in a 'relativist' way (namely that reality is accessible only through individuals' representations of the world (Burr 2003)). In contrast, scientific research, based on 'experiment and observation' is of the 'positivist' tradition and was widely viewed by academics as the best way 'to obtain reliable knowledge about the world' for much of the last century (quotations from Machamer 2002 p2). Epistemology, the study of knowledge has a role to play in assessing the relative contributions of positivism and more experience-based philosophies. Newnes (2001) states that 'we need a greater acceptance of a far broader range of evidence than is the case at present with a particular emphasis on what might be described, or even decried as, non-scientific evidence; the evidence of literature, our senses and personal experience' (p14). Faulkener and Thomas (2002) posit that in terms

of user involvement in research, perhaps ‘a marriage of two types of expertise is the essential ingredient of the best mental health care: expertise by experience and expertise by profession’ (p3). This marriage may yet be volatile, with cynicism on both sides (Kelson 2001).

1.13.1. Philosophical Accounts of ‘Knowing’

The problems inherent in effectively including experiential evidence alongside ‘positivist’³ evidence are reminiscent of epistemological dilemmas that have been a feature of psychological philosophy for many years (positivism versus phenomenology), and can be traced back to Husserl’s Logical Investigations in the 1900s (Gregory 1987). Stickley (2006) describes critical realism as a theory that disputes the customary cleft between natural and social sciences. He describes it as not just asking ‘how did the explosion follow from lighting the dynamite?’ but ‘who lit it?’ and ‘why?’ (p571). He adds that it recognises ‘not only the reality of the natural order but also the events and discourses of the social world’ (p571). As such this perhaps provides a suitable backdrop for investigating guidelines that purport to make use of different ways of knowing, and the power dynamics inherent in convening groups of people, particularly those involving actors from both empowered and disenfranchised roles in mental health services.

Social constructionism is another relevant philosophical position, which critiques the notion of taken-for-granted knowledge, paying attention to language, and the way in which it epitomises the traditional assumptions and ideas held by a particular culture (Dallos and Draper 2005). Service users arguably occupy a unique, often reviled, role in British culture, a role that clinical psychologists perhaps aim to understand and improve. The extent to which service users describe their involvement in NICE guidelines as valued and meaningful may then be a cultural thermometer. Service user assumptions may be consciously or unconsciously communicated by the language used when reflecting on the ‘involvement’ process. These assumptions may reflect changes or ‘stuckness’ highlighted by the process of guideline development or even the act of

³ The term ‘science’ will be used in the context of interviews as this was the terminology used by them

enquiring about it. As GDG members whose jobs are predicated on developing close relationships with service users, psychologists may have a valuable role in enhancing user involvement in this context.

Positivism, an epistemology (or how we come to know the world and what can be known) that underpins scientific experiments such as RCTs (Randomised Controlled Trials) asserts that knowledge should be objective ‘impartial and unbiased...without [the influence of] personal or invested interests of the observer’ (Willig 2001 p3). In the context of developing guideline,s an example derived from positivist practice could be the guidelines for prescribing medication that is effective in reducing auditory hallucinations.

Phenomenology, in turn, is a philosophy and epistemology espoused by people ‘interested in the world as it is experienced by human beings in particular contexts and at particular times’ (Willig 2001 p51). From a phenomenological perspective, service user representatives may be recruited to GDGs specifically to recount personal experiences in order to be ‘involved’ in reaching decisions about recommendations. Phenomenological knowledge could be obtained through service users expressing their preferences for certain medications over others based on their side effect profiles, or “what is it like” to take a particular medication, for example.

Epistemologically, these positions seem opposed, and in practice they may be difficult to reconcile. Developing guidelines based on scientific knowledge or phenomenological knowledge alone, may be problematic. However, when these two different kinds of knowledge are used together they may be complementary. That is, what cannot be answered from a positivist, scientific perspective may have an answer from a phenomenological perspective.

1.14. The Present Study

This study seeks to explore the ways that service users experience participation in NICE mental health GDGs. The difficulty in reconciling user experience and research-based positivist ‘scientific’ evidence will be a focus of the study, given the evidence and concerns listed above. The outcome of more integration between users and professionals in guideline development may indicate that the process is becoming more user-centred. This could mean greater acceptability of recommendations, greater satisfaction with the process by patients, professionals, the public and policymakers and greater inclusion in decision-making in other domains. These ideals map onto the Department of Health’s mandate and the BPS’ ethos of partnership working and may have a broad effect on the practice of psychologists and other professions and their resultant impact on service users.

The above discussion has highlighted an interesting aspiration for the contrasting data used in NICE guidelines (evidence and experience), that recommendations are ‘evidence-based’ and that service users are involved. By virtue of involving service users they should also be experience-based. As the above discourse suggests, this is not an easy process. NICE guidelines are produced by teams including psychologists who (according to the BPS (2001)) should develop relationships with service users characterised by collaboration and consideration of power issues. As the resulting guidance impacts on the day-to-day work of clinical psychologists, service users’ involvement in GDGs is an important area of investigation and prompted this study to ask: ‘How do service users perceive their involvement in NICE guideline development?’

This study therefore adopts a qualitative perspective to gain a deep insight into the experience of service users. Service users may be viewed as ‘involved’ in guideline development merely by virtue of being present at meetings. However, eliciting their experiences and views on how involved they feel may produce a more rich and more relevant picture of involvement in GDGs. Bryman (2001) outlines that qualitative research can explore data which is reconstructed from participants’ experiences, beliefs

and motivations surrounding the phenomenon being studied. Spencer *et al.* (2003) describe qualitative methodology as being characterised by ‘a commitment to viewing (and sometimes explaining) phenomena *from the perspective of those being studied*’ (their emphasis, p32). Finch (1986) describes how qualitative approaches to policy evaluation can ‘compare the assumptions upon which policies are based with social experience’ (p158). The parallels between policy development and the process of writing NICE guidance suggest that qualitative methodology may be the best approach to fully examining the perceptions service users have of their involvement.

A qualitative perspective was adopted to elicit and analyse data, gathered through semi-structured interviews. Grounded Theory (GT – Glaser and Strauss 1967) was employed. GT was used as it allows ‘a systematic representation of the participants’ experience and understanding’ (Willig 2008 p45) to be developed, so the generation of a theory grounded in the data is possible. This is important as little theory about the reality of user involvement in GDGs exists, other than that elicited from ‘professionals’. Understanding service users’ experiences may add a new perspective to accounts that exist so far and identify barriers and facilitating elements. GT also aims to examine social processes, from the participants’ perspective, ‘from the inside out’ Charmaz 1995 p31). An abbreviated version of GT was used (Willig 2008) as this is more appropriate than the full version for a study such as this which is limited in time and resources. The difference is that abbreviated GT works solely with the original data and no new data are introduced as the data are analysed. Charmaz’s version of GT methodology is most appropriate for this study as it adopts a social constructionist approach, assuming that the researcher discovers their ideas about the data ‘after interacting with it’ (Charmaz 1990 p1169). This appeals as it accepts that the researcher plays a part in organising the interpretation (Willig 2008). GT was selected over a competing methodology: Interpretive Phenomenological Analysis (IPA) which shares some of these advantages but does not usually involve examination of the interplay between units that emerge (in GT these units are categories, in IPA these are themes). IPA was discarded as it traditionally describes rather than explains data and is more suited to exploring individuals’ psychological worlds, whereas the present study focuses on involvement, which is interactional by

definition. GT also allows the study of 'localized social processes' (Willig 2008 p45), those that emerge in a particular context, here GDGs. In summary, Charmaz's version of GT was used as it respects the individuality and autonomy of both researcher and participants. In discovering theory about personal experiences of social processes within the context of GDGs, GT suits participants' contexts better than its closest rival, IPA.

1.15. Service Users in Research

The context of the researcher (i.e. service user or mental health professional) has been highlighted by some as possibly influencing the research process. Faulkner and Thomas (2002) suggest that user research 'examines images and outcomes that are relevant and meaningful to service users'(p2). This does not preclude researchers with other backgrounds, using appropriate questions and methodologies, from examining similar areas. Simpson and House (2002) report however that clients of services interviewed by other service users reported less satisfaction with services. Participants in this evaluation perhaps felt more able to be honest with other service users, or conversely felt they had to act as 'critic' when interviewed by other service users.

Interpretive Phenomenological Analysis (IPA) utilises a 'double hermeneutic' approach (Smith and Osborn 2008, p53, in Smith 2008) in that the impossibility of direct access to the participant's world is accepted and that the researcher acknowledges they interpret the participant's interpretation of their experiences. IPA approaches might mean that the researcher's and the participants' experiences may have a common framework that informs the analysis. However the diversity of service users' experiences and the researcher's co-existing status as mental health professional may impact on the direct relevance of this approach. Service users may not be the only group of people able to effectively collect data on service users' experiences – as long as reflexivity, which some authors link to counter transference between researcher and participants (Willig 2008), is attended to.

2. Method

2.1. Ethical Approval

A proposal for this research was submitted to Surrey University (appendices A and B). After this was approved the Central Office for Research Ethics Committees (COREC), the NHS ethics body was also contacted but its approval was not required as participants were not recruited by virtue of NHS affiliation (appendix C). A favourable opinion was given by university ethics (appendix D). NICE also returned a favourable opinion (appendix E).

2.2. Participants

Potential participants were identified from the College Research Unit (CRU – a collaborator alongside the BPS in developing NICE mental health guidelines) database (using the criteria below) and initially contacted by the researcher's field supervisor, in order to preserve the anonymity of guideline contributors. Inclusion criteria were that individuals were service users who had contributed to a NICE mental health-related guideline within the last 18 months or were awaiting publication of one. Exclusion criteria included lay members of groups who were not themselves service users.

Invitations were sent to twelve service users, who were contacted both by post and email and given brief information about what to expect from participating (appendix F). They were asked to return a slip if they were interested in finding out more with a view to possibly participating. Nine positive responses were initially received (a response rate of 75%). An information sheet and consent form (appendices G and H) were sent to each individual with an invitation to ask any previously unanswered questions. The nine service users were pooled from two separate waves of invitations being sent out. A tenth was recruited by the field supervisor contacting one individual who was involved in an ongoing guideline development group. This individual accepted the invitation to be involved. Each of the ten participants was interviewed, representing nine different

guideline development groups. Five participants were female (50%) and all self-identified as being of white British ethnicity. A range of educational and work experiences was represented. Participants' 'representativeness' of GDG service user members was not sought by the present research. That is, this study adopted a qualitative approach under which results are not generalisable but transferable. Therefore, the results of the present research can only be compared to the results of other research with similar samples, in a similar socio-historical context and using similar methodology. Equally, the results of this research are only applicable to samples similar to those used here (see Willig, 2008, for an extensive discussion of no-representative samples in qualitative research). The titles of the guidelines represented have not been listed in order to protect the confidentiality of the people who agreed to take part: They had been assured that their comments would not be traceable back to them. As participants came from a relatively small and highly identifiable group this meant that further demographic details have been withheld and all names used are pseudonyms.

Theoretical sampling refers to the practice of seeking further participants in the light of new findings emerging from the analysed data. The concept is prescriptive to the GT method as originally devised by Glaser and Strauss (1967). In this study, theoretical sampling was used to further enquire into the insights that the data yielded as the interviews proceed, by interviewing participants on the same guideline consecutively and employing an iterative approach to developing the questions asked.

2.3. Procedure

2.3.1. Interview Schedule

This research used a semi-structured interview schedule (version 1 appendix I). This consisted of general questions supplemented by prompts as the interview progressed. Qualitative researchers often use semi-structured interviews as this format allows the researcher to maintain a degree of control of the interview while allowing the participants to follow his/her insights and interests (Smith 1995). In addition, Charmaz (2006)

suggests that semi-structured interviews can be useful to novice researchers, as they help to guide the researcher and to fulfil the requirements of ethics committees.

For the schedule, an initial pool of 42 questions was reduced to a core of 7 (plus some demographic questions) with prompts. Following a prescribed method of Grounded Theory (Charmaz 2006), the original schedule was revised 4 further times. Revisions occurred after interviews 1, 3, 6 and 7, to ensure that emerging ideas were explored in depth in successive interviews. The final semi-structured interview schedule was therefore different to the first (appendix J).

2.3.2. Interviews

Participants were each interviewed for approximately one hour. Interviews were taped using an electronic recording device or telephone recording device, then transcribed as soon as possible after the interview (using a word processor), and analysed. An iterative approach to data collection and analysis was used with members of the same guideline interviewed consecutively to explore emergent themes, and as such employing theoretical sampling. Earlier participants were contacted for their thoughts on ideas inspired by later participants. The third participant requested information on findings that had emerged so far. This opportunity was used to discuss the ideas that were then being considered. This ‘credibility check’ was useful in reinforcing the direction the analysis was taking and checking it was meaningful to the experts being interviewed – the service users.

Constant comparisons were used to ensure the analysis remained grounded in the data. These involved comparing data between and within transcripts. This was to ensure that ‘all instances of variation [were] captured by the emerging theory’ (Willig 2008 p37). A summary of the categories that emerged (appendix K) was circulated to the ten participants, each of whom had agreed to offer their feedback. Seven people responded and suggested it appropriately captured their views (see appendix L for an example), though some were more passionate in their agreement than others. This element (as well as checking the analysis after the third interview) was introduced as a credibility check,

to ensure that the analysis summarised and expressed rather than inaccurately interpreted the views of participants. This is particularly important in qualitative research and meets Whitley and Crawford's (2005) recommendation that participants are given the opportunity to comment on the researcher's inferences.

2.3.3. Reflection and Reflexivity

Charmaz (2006) describes the role of reflexivity as 'the researcher's scrutiny of his or her research experience, decisions, and interpretations in ways that bring the researcher into the process and allow the reader to assess how and to what extent the researcher's interests, positions and assumptions influenced inquiry' (p.188). . This section is included here, so that the analysis can be read with the researcher's context in mind (Finlay 2002). Chamaz describes the way in which issues such as 'class, race, gender, age, embodiment, and historical era may permeate and analysis without the researcher's awareness' (p68). She adds that constantly challenging and being mindful of preconceptions and assumptions is necessary in order to stay alert to imposing a framework on data that is not warranted. I had been in the place of many of the participants – being a former service user representative on a NICE guideline development group and a service user. I was also pursuing research critical to my clinical psychology doctorate suggesting an impetus to relate the study to the practice of psychologists. I had felt it necessary to be open with research participants about my interest in guidelines stemming from personal experience of being a service user representative myself. This was to make my starting point clear and to encourage participants to speak freely about their experiences. Some asked questions about my experience, which felt a little uncomfortable.

As a former service user representative I⁴ came to the research with some ideas about what I would find, though I tried not to look for them. This meant being true to participants' perceptions and being alert to the danger of forcing data to fit my preconceptions. GT was iterative in this context as the methodology reflected the phenomenon being studied; guidelines (theory) emerged from a finely balanced

⁴ Again I will use the first section to facilitate reflexivity

deliberative process (strategic analysis) and aimed at describing highly complex decisions regarding the role of the service user. It was a privilege to have the opportunity to talk to so many dynamic and passionate people. I have learned a great deal from the research process. The people I spoke to were candid about their disappointment with parts of the process and exuberant in their praise when it had gone well. I found that user involvement was more active and had permeated more deeply through the guideline development process than I remembered, though participants had generally been members of GDGs that started some years after the ones I contributed to were published. I have developed academically, personally and professionally since sitting on a GDG myself and I am pleased I was able to let go of earlier convictions in the light of new knowledge. I started the study being optimistic about psychologists' roles in facilitating involvement of service users but this idea was moderated by the experience of undertaking the research. I feel that a romantic notion about psychologists being the sole champions of user involvement and holding the GDG together, using their training and innate sensitivity to seamlessly bridge the experience – evidence gap, has been challenged. I believe the difficulty some service users had in distinguishing between psychologists and psychiatrists may be a function of all mental health professionals being human and having individual personalities. A further explanation may relate to service users perceiving the role of professionals as being generic or psychologists trying to emulate psychiatrists (Parker 2007). Rather than stating how my own context has shaped the study, as advocated by Charmaz (2006), I invite the reader to draw his / her own conclusions about its impact.

2.3.4. Analysis

The interviews were analysed following a prescribed method (Charmaz 2006). The transcripts were first read closely to facilitate immersion in the data. This served to start the process of identifying similarities and differences between and within each person's account. The next step involved coding each line of data with an active statement about what might be being communicated, these active statements tended to use verbs rather than adjectives. Focused coding (that is naming ideas that join larger clusters of the initial

codes together) followed. This was achieved by identifying ideas that emerged that belonged on the same continua, such as satisfaction and achievement being positive emotions. Focused coding led to writing memos - grouping quotations from transcripts that addressed related concepts together under a common title. Memos contained focused codes that covered many related continua, including opposites and moderators. For example 'speaking a foreign language' contained focused codes including notions of people feeling out of their depth when confronted by jargon, as well as the idea of the chair's role in ensuring everybody understood as being a great leveller.

Data were continually reanalysed as these groupings developed, meaning that memos were expanded, collapsed together and redrafted to accommodate new transcripts. Earlier interviews were reanalysed after new memos were developed, to establish whether data they contained could inform memos that had been created since the transcript was initially analysed. 'Saturation' is the point at which no new data are emerging from interviews. Though complete saturation is difficult to achieve within a study as time-limited as this, the extent to which areas were being replicated rather than innovated suggested the process was thorough. After the 6th interview, the 126 existing memos were sifted and clustered together to form 4 categories. The remaining 4 interviews were based on interview schedules that were further elaborated to explore areas that arose from this process.

The study resulted in a 'map' of influences on service users' perceptions of their involvement in GDGs – details are given in the 'results' and 'discussion' sections below. This is described using a metaphor, which is a vehicle for explaining links and ideas, but does not constitute a 'theory' - as it does not explain the processes underlying the dynamics described. To fully generate a theory the present study would have had to have reached 'saturation'. In grounded theory, 'saturation' is said to have been achieved when no new threads or ideas emerge from the data and interviewing further participants is thought not to yield further insights. For pragmatic reasons, saturation was not possible in this study.

3. Results

Although participants differed in gender, age and cultural background, common themes were found in the transcripts (see appendix K for an example transcript). Four categories were found to emerge from the data. These were: 1. 'People Interacting: Getting on with it'; 2. 'Components of the GDG: Contrasting the Raw Materials'; 3. 'Powerful Product, Rigorous Process: Predetermined but Unclear Operating Rules' and 4. 'Balancing components to generate the product'. These categories are explained below with the help of a metaphor used to link the work undertaken by guideline development groups with teams creating machinery or tools for use by others.

3.1. Producing a Tool for Public Use

This analysis is grounded in a metaphor used by one participant about a GDG being similar to a group of people with varying skills and experience developing a new car:

'...It's like maybe its like designing a high performance motor car with a team of engineers and designers and all the professionals that are needed to do, design that car and then there's someone who you know takes their J reg. Renault occasionally out for a spin...' (Evan).

Service users, being lay members, are likened to infrequent drivers – in contrast with experienced professionals who are construed as engineers and designers. The metaphor is extended here to include creating a product or tool for public consumption. Although GDGs are unique and deserve description in their own right, the metaphor is used in the analysis in a novel way and serves to link the GDG phenomenon with entities or processes which have already been described. The tool or machine produced is to be of the highest specifications and represents the 'cutting edge' of technology and knowledge. The metaphor allows the rich description of the nature of and relationships between interpersonal and decision-making processes and the desired or final product. The people involved are stakeholders in this product in different ways, with some more personally invested in the outcome than others. Team or group members have varying levels and

types of expertise to contribute. Lay members and technical experts must co-exist but form coalitions and alliances within the group. These interactive processes can help or hinder the development of guidance as described below:

3.2. People Interacting: Getting on with it

GDGs involve a group of differently experienced individuals gathering together to perform a sophisticated task and having to form a team. This category emerged from people's descriptions of group members finding ways to work together, sometimes building on one another's strengths to move towards what is later described by some as a common goal. To develop a sense of synchrony, people had to talk and service users described being sensitive to signs of being categorised, in both formal and informal conversation.

Interpersonal skills were of utmost importance in generating an environment where people could work together. With a group of people convened to develop a complex tool or document, the roles they assume (the rivalries and alliances or frictions that developed), could have a wide-reaching impact. Several participants outlined that it was relationships with other service users they found hardest, being concerned about sharing views or being from different backgrounds. In addition many service users noted that professionals were more similar to one another and as such gravitated towards one another. However interdisciplinary alliances did occur – to use the machine metaphor, parts of different shapes and sizes could work together. Steve pointed to an example of a collaborative alliance he had developed with a psychologist, suggesting reciprocity in their relationship and the potential for 'groups' within the group to give and take and maintain homeostasis:

'I had begun to complement them with anecdotal evidence to match their evidence base and practice experience so it had started to grow into something that was collaborative'. (Steve).

Psychologists were commonly viewed as being generic parts of the GDG, almost indistinguishable from other professions (particularly psychiatrists), though when further questioned some people felt that psychologists were heterogeneous and as such did not occupy a circumscribed role. Clive elaborated on the former point and critiqued the position:

'I suppose [the psychologist's] views were so similar to the psychiatrists most of the time that, I suppose very research oriented and career oriented I didn't much, it didn't really register with me that he was a psychologist most of the time'. (Clive)

This was perhaps a reflection that psychologists were adaptable as tools. There were some further positive stories of psychologists being the most collaborative in their relationships with service users, for example Beth said of those in her group:

'They [psychologists] are more likely in the group to invite service user comments um and um certainly it, it, you feel when you do contribute that they'll be the people who kind of take on what you say' (Beth).

As an often disenfranchised group, some service users expected their input might be minimised. An informal 'blueprint' for the guideline document being developed by the GDG already existed (the scope) and some group members felt they were expected to 'play the game' and work on NICE's terms in order to be listened to:

'I mean I think it was [name of group member] at the beginning who said early on, quite clearly you are gonna have to accept this is how NICE works and you have just got to lump it. i.e. you will have to work with it as best you...if all we present is a series of best practice points because there is no good evidence, no good evidence to back it up then the guideline will have no teeth' (Leah).

The message from this participant seemed to suggest there were ways in which service users and professionals alike were expected to engage with the evidence base.

As team members were of assorted origins they could each be potentially accorded a different status. Service users felt they were perceived as having less sway and some predicted power differences. At the beginning of the team's time together, people were trying to find their niches, ways they could positively contribute to the development of the machine.

'Erm I think to start off with, um there was as I said a bit of posturing and a bit of power positioning, and I think um that can be a lot of problems because as a service user there are always these power differentials between the professionals and the service users' (Christine).

Psychiatrists were generally seen to have the most power. Some interviewees (not all) suggested that psychiatrists merited this by having 'strength' in the most relevant knowledge:

'It was very led and dominated by the psychiatrist obviously, because they...they were the ones who knew the studies and understood it all'. (Evan).

Therefore, for different reasons (e.g. profession, communication skills) members often played out the Orwellian maxim that 'some [were] more equal than others' (Orwell 1945). The team therefore had unofficial leaders but this did not necessarily impede them from coming together to devise their new tool.

3.3. Components of the GDG: Contrasting the Raw Materials

Contrasting the raw materials refers to reflections on the different components or types of evidence used in the development of the machine and the essential characteristics of those 'eligible' to champion them. The 'contrast' aspect is exemplified by the recognition that 'scientific' and 'experiential' knowledge are of very different origins. There were however some points where they overlapped. In the process of analysis it became

apparent that GDG members each both advocated for and examined the applicability of these components.

3.3.1. Scientific Components: Quantifiable but Limited Availability

The scientific input to the guideline development ‘machine’ was perceived as orderly, concrete and difficult to understand for the uninitiated. Some people had less prior experience or exposure whilst others had a more sophisticated understanding.

There was generally agreement that scientific approaches provided concrete evidence that was appropriate for certain tasks:

‘Certainly the drugs that was the easiest thing because there is better statistical evidence for the drugs and that was a very very important thing that the guideline did, that very clear advice about drugs that had been lacking before.’ (Leah).

However, in contrast there was fairly general consensus that one size does not fit all and scientific evidence as a component was limited in its availability and usefulness. Julia described the issue of scientific evidence not existing for many topic areas:

‘It turned out that actually there wasn’t much evidence anyway which was quite an eye opener for me’

And Beth mentioned the jobs scientific evidence could not assist with, suggesting there were problems in getting the components to fit:

‘If it is not RCT evidence then it is not not worth considering. I really struggled with that because they tend to be the treatments that are better suited to RCTs anyway, they’re cheaper therapies to run’.

3.3.2. Experiential Components: Adaptable for use by Anybody but Limited in Applicability

The other key component was service user experience. This was a more abstract concept and its influence was harder to define as it took many guises. Participants reflected on the nature of experience used (not solely personal examples) and that it was not only service users that used experiential examples suggesting that experience is an adaptable component. There was a concession by some service users that ‘experiential evidence’ did not always benefit the process of assembling the guideline. One participant described the way in which some service user points did not fit the mould that made data useful in achieving the group’s task, citing the example of a service user colleague:

‘He didn’t have the sort of skills – his contribution could only be, you know banging on about the same old points from his experience that couldn’t meaningfully be fed into that process’ (Evan).

The types of experience used were varied, Clive reported a view in common with other participants, that it was not always specifically personal examples that were fed into the process:

‘I don’t remember talking about my personal experiences.... I obviously drew on them, but I didn’t, I don’t remember being specifically asked about them’.

And the experience was not always owned by the person contributing it:

‘In my case I have had lots of personal experience but also lots of personal contact with lots of other service user reps don’t forget so I am not just talking from my own personal experience’ (Steve).

Thus experience was not always used directly but could inform people's input once it had been processed by the individual. Evan used a powerful vignette to describe the limitations of service users in producing guidelines. This provided the inspiration for the 'machine' development metaphor used in the analysis of data:

'It's rather like, I am just trying to think of an analogy, its like maybe its like designing a high performance motor car with a team of engineers and designers and all the professionals that are needed to do, design that car and then there's someone who you know takes their J reg. Renault occasionally out for a spin and they are invited to comment on how they would like this high performance car to be designed – all they can do is a few things about how they want their cars to feel and drive but they don't really have specialist professional skills – they're not, they don't represent, they don't work for the AA or RAC like they ought to represent tens of thousands of people's views on cars, they are just one individual with their own views' (Evan).

Participants also commented on advantages gained through service user experience being fed into the development mechanism. It is described as benefiting both the process and the end product. The unique contribution that service users make when present at proceedings was cast in several ways by different interviewees. For example providing a space to reflect on the implications of recommendations. Unlike Evan's vision of service users being uninitiated in the essential technology, Greg describes the valued difference in perspectives that exists and the need to consider the service user's point of view:

'I would make the point that we are the experts um, the professionals are experts in their own ways but they are not 'the experts'... we see the world from the inside out, whereas they see our world from the outside in. so we have a viewpoint to express that is very practical, very down to earth and something we have been exposed to' (Greg).

The concept of service users acting as a 'failsafe' to prevent unhelpful ideas from gaining power was reported by several participants:

'I have called myself like the language police really' (Beth).

And Clive added a sense of how user involvement could add credibility to the tool by its development process being 'witnessed' or 'quality controlled' by service users:

'I think it means the process has been...you know witnessed by relatively lay people, you know service users and carers and it hasn't just been put together by professionals in a smoke-filled room'.

When asked about how she saw her responsibility as a service user representative, Jane implied this described the value of service users on GDGs as keeping the whole person (being more than the sum of their symptoms) in mind, a sentiment echoed by many other participants:

'To make sure that the actual experience of [disorder] and the person does not get lost, the experience of someone you know living with it on a day-to-day basis was never forgotten...it is not forgetting what the person is experiencing at home on their own'.

A frequent theme was the value of service users in defining the 'specification' (scope or priorities) of the guideline, directing the guideline development process in a way that displayed the relevance of their experience:

'They certainly used the questions I had come up with to inform how they went about gathering the evidence and structuring it, that was positive actually' (Julia).

Despite their very different contributions, service users and professionals both used personal experience. Service user experience was described as being 'unlearnable' or impossible to manufacture artificially, though non-lay members used their professional experiences to illustrate debates. Experience is then perhaps an 'all-purpose' component:

'Some of them worked very much by talking about people they are actually working with at the time – people they had seen, or to illustrate the case for designated beds...or whatever it was they wanted' (Leah).

It was unclear whether professionals' use of experience was different to that of service users. Both contributed to 'good practice points' though it is possible that professionals might report their colleagues' experiences in a different way to service users describing the experiences of other service users because of potential professional rivalries.

Using experience was not a default position however, when asked about times she remembered her experience being sought on a subject, Christine talked about how she had to be quite assertive to get a point in.

'[Experience was given] only when we interjected...I didn't really feel though that there was much probing, people wanted to volunteer the information more than specifically ask you'.

When asked why she felt this was she suggested it was protective:

'Probably erm, they were frightened that we may...become upset'.

Professionals were then using their training and empathy, which was viewed positively. This may possibly perpetuate the service user's identity as 'patient' rather than colleague or it might demonstrate respect and consideration for an individual's privacy.

3.3.3. Specifications of 'Good' Team Members: Mastery of Tools of the Trade

Curiosity about which characteristics did or would make for effective team members suggested service user representatives might need to be 'potent'. Almost everybody outlined that 'just' having the 'relevant' mental health problem was an insufficient prerequisite for working effectively within a GDG. Both intrinsic 'personality'

characteristics and external experiences were listed as important, if not vital to successful involvement. Most people had been recruited by virtue of 'becoming known' within charities, or for other involvement work they had partaken in. Potency in this context refers to being powerful, confident and productive. A huge proportion of participants talked about the usefulness of prior experience of research. Another important factor that came across was experience of meetings and being motivated to prepare for the task which might act as a kind of prototype for what is a novel task.

'I think they [successful user representatives] have to be able to interpret research,... and read around the area as much as you can...And you have to be able to speak in a large group, and that is to go into a large group if you haven't been used to committees is very daunting!' (Christine).

Christine also suggested that some distance from the distress experienced as well as an ability to empathise with professionals' perspectives is helpful:

'...I mean also we have to be able to understand...you have to sort of put yourself in their shoes as well to understand their working to a sort of extent'.

To be successful psychologists should have in-depth specialist knowledge along with what may be termed 'therapeutic skills'. Soft 'people' or therapeutic skills including listening skills or being open-minded. also merited attention. Christine made a plea for psychologists to be more open to experience based research, perhaps another way of combining scientific and experiential evidence to create a more sophisticated product:

'[Psychologists should be] A good listener, got to be a good listener, and be a person who is very open, not rigid in their thinking – somebody who, obviously I am very biased, somebody who gives weight to qualitative evidence!'

As such both service users and psychologist required an ‘x-factor’, extensive involvement, interpersonal or therapeutic skills – effectively exemplary mastery of the tools of their trades.

3.4. Powerful Product and Rigorous Process: Predetermined but Unclear Operating Rules

The term ‘Rigorous Process’ is used to convey the formality and concrete yet arbitrary nature of the processes of crafting NICE guidance. This was reminiscent of a machine having only one mechanism that cannot be digressed from. The notion of the product as powerful reflects the importance of the precision with which it is created – again implying little room for distraction from what can be a predetermined blueprint. As such there were traditions and specific preparations that were key to the development process. There was also a kind of awe or respect for the task that impacted on individuals’ predictions about what would be involved and on individuals’ reflections on it after the development had finished.

‘Testimonials’ by people who had experienced a particular disorder were often included as the formal illustrative examples in the text. They were used to illustrate, highlight and draw together issues raised by the content of each guideline and perhaps represent a ‘guide’ to the guideline:

‘We have several testimonies of people writing about their own experience of [disorder]... I think it was to bring in the range...because a lot of people think they know what [disorder] is, and it is so much broader’ (Jane).

These statements obviously made the finished product more powerful in the eyes of the service user representatives, though it is unclear what professional contributors or readers might think. Others noted their disappointment at the lack of testimonies in the guideline they were involved in. People perhaps expected that a document that could have so much impact on people’s experiences should automatically include examples of the situations

they referred to. The absence of points of reference perhaps made service users worry the guideline would be impenetrable to non-expert readers.

Service user representatives displayed some awe for the 'scientific component' of the research evidence and reported concerns about the level of expertise their 'evidence' would be accorded. Service user team members also expressed worries they initially had about tokenism in the face of an established system, being there for show rather than being a 'moving part' of the machine. Linked to this was a worry about the magnitude of the individual's perspective in contrast to the experience of the 'experts':

'I thought 'here are all these very professional people, the experts...and there's little old me that's had this experience and it was a long time ago' (Christine).

Training in the guideline development technology – the systematic review process - was provided. This aimed to increase lay members' expertise so that they had the tools they needed to effectively contribute,. Service users without relevant qualifications uniformly felt this training was insufficient. Being aware of but not masters of the technology involved left service users at a disadvantage:

'I think she [the trainer] was a statistician, and she came along and had several of those and showed us a book and people just said erm, yeah and nodded [laughs] and we would think 'hmm, we believe you!' [Laughs]' (Christine).

To complicate the difficulties in agreeing what the tool should look like, most interviewees talked about decision-making processes not being formalised Evan corroborates this view:

'Um I was a little bit unclear about the process for decision-making because you know I don't think it was ever set out from the beginning how, how decisions were going to be reached and whether there was going to be a you know voting process or something like that'.

In order to make such difficult decisions, information should be clear and shared within the system, NICE uses the internet to facilitate communication but some people suspected they were excluded from the loop, though there was a reference by one interviewee to this being a relief:

'[I was] very glad not to have been copied in [laughs]' (Leah).

Service users reported other ways of being prevented from contributing usefully to the whole process. This was due to the mechanistic established methodology, which was often a 'closed system' that could not flexibly include experiential views.

'And it wasn't 'til the later stages that there started to be a more objective look at what they wanted to emphasise. And the very, nine-tenths of the process was a very rigorous, dry process, looking at all the evidence and sifting through it which was all sort of tedious and effortful' (Evan).

Though people were not necessarily happy about the inalterable conveyor-belt like mechanism of guideline development, there was a recognition that it had to be specified to a high calibre and include the best quality materials:

'It's a national guideline...there's a bit more to that [than personal experience] isn't there? Once you looked at the scope of the guideline. So I understood the reason for it it has to be essential, there has to be something about this' (Steve).

A suggestion Evan made about methods for generating 'higher quality' service user evidence was echoed by many participants.

'I don't know whether you know focus groups of research, you know commissioning research among service users, like that would could have a role' (Evan).

They felt this might provide them with a tool to help them shape user involvement on the same terms as professional contributors and enlarge their role and contribution.

The self-determination and power of GDGs were limited in some respects, as their recommendations could be seemingly arbitrarily overridden by '*shadowy figures*' (Leah). This may reflect the 'blueprint' being predetermined by unseen operators exerting their influence. Several service users reported conclusions reached by the group being vetoed by NICE:

'Um, again I feel that there was a certain amount of consensus as a group, um and we were led as well by the people, the NICE employees, the collaborating group who were actually leading it and they would say 'Oh its not going to work' in terms of how the guideline was going to look at the end' (Jane).

Leah described her negative feelings at this phenomenon when it occurred in her group:

'It felt dismaying, I mean I wasn't directly overruled but to feel one's position kind of organised out of it, the voice, the voices of the group got pushed um, aside'.

3.5. Balancing Contributions to Generate the Product

'Balancing components' described participants' perceptions of the ways the evidence (components) was compared and contrasted by team members to inform recommendations, the bulk of the guideline (the product). The precise and delicate nature of the balance is highlighted by both the process and the product. The components include the team and the product, as well as the process which united them. The team are experts developing a machine but also function like a machine, with members acting as differently sized cogs exerting differing amount of leverage.

3.5.1. Characteristics of the Product: Users' Influence on and Satisfaction with the Tool Developed Vary

Service users could enjoy the process and the product differently, Steve referred to his disagreement with the content of the guidelines he was involved with, despite his overall positive experience of the development process:

'The running joke within the guideline with me and the professionals was 'You are completely against the whole ethos of this aren't you?'

Others described how they found parts of the product helpful for the end user, Beth said she felt that good practice points might be useful, being based as they were on expert opinion. They may be a practical way of applying the broader expertise existing within the group. She had however reported some dissatisfaction with the process elsewhere (see earlier).

'We have made some good practice points, I am hoping that it will maybe change some practice'.

As such the value of the product and the process were not interdependent. Some people made suggestions about how the process could balance scientific evidence with more qualitative evidence. Clive felt it could be incorporated into the guideline in a way that was self-limiting:

'If a broader range can be considered, you can still include in the guideline levels of certainty so you can still say there is qualitative, experiential work which suggests...we don't activate claims that go beyond the evidence but we can still note it and record it into the guideline'.

3.5.2. Technical Language Difficulties: Professionals Speaking a Foreign Language

In order to come together as a team, a shared language was required. A pervasive idea was that of technical jargon (acronyms and ambiguous terms) resembling a ‘foreign language’, which could stall the process. This links with power differences described earlier:

‘I’m not used to being in that field with so many experts around me...talking fluently about their subject...it just came across as a little bit daunting’ (Joe).

Technical language was for some frustrating but others did not allow it to prevent them from making meaningful connections and contributions:

‘As far as I am concerned a language is only a discourse and a discourse is for me, well languages can be learned’ (Steve).

Others spoke of the value of recognising ambiguity and translating difficult terms in ‘levelling the playing field’ and preventing lay members from being blinded by science:

‘We had a very good chair who said ‘Explain that’ or would actually say ‘I don’t understand what you mean by that’ when I knew jolly well that they did know and it put them [unclear communicators] in their place. And that was quite good I think. (Christine).

The difficulty in understanding complex language was reported by most people and it is likely that other members of GDGs struggled at times. Some professionals perhaps erroneously assumed they could be understood without clarifying the acronyms and abbreviations that permeate the health professions. It seems the development process requires a technical manual or glossary!

3.5.3. Characteristics of the Process: Multiple Perspectives Combine

Reconciling the apparently ‘opposing forces’ of science (positivism) and experience could involve compromises, consensus and conflict. These disruptions were based on professional, personality and interpersonal differences. Making decisions about the design of a product means some people do not get their way, potentially disrupting the harmony of the production line. Several participants referred to the extent to which they felt they had deferred to the knowledge of the professionals, the ‘default’ expertise, but felt confident in doing so:

‘I often didn’t have a lot to say because I was very confident in what they were saying. I would just say ‘I agree with that’ ... so it was just confirmation’ (Jane).

Beth felt more frustrated with this process of trusting the professionals on certain decisions because of the absence of the relevant tools and the rigidity of the process:

‘You go along and agree with what they are recommending because you can’t criticise their interpretation of the evidence, you don’t have the ability to critically evaluate anything they are saying because you don’t have the knowledge or the experience in the field to do that’.

Evan talked about how guidelines must retain the real service user as the focus of deliberations, and respect their individuality alongside a recognition of the clinical judgement of the ‘operator’, the practitioner:

‘...As a patient myself you want the best at NICE and...it is kind of knowhow and experience, someone who is really experienced in treating the condition can say ‘Well this is what the evidence is but that didn’t work so there is no point in trying that again’ or ‘This tends to work quite well with you but there’s not a lot of research’ its special, the benefit of experience...’

Service users did not assume that user experience and scientific evidence were incompatible and unable to work in harmony, though they explained different concepts, as Jane outlines:

'I don't think they were ever in conflict, yes they did compliment each other [science and experience] but I think the actual experience of living with [disorder] is always so much broader than coming down to technical research issues which might be about which [medication] worked better, which one do we have the evidence that shows one seems to be more effective than another and you start getting that technical evidence that comes down to such small points and you think the living experience is...much bigger'. (Jane)

This implies that highly refined research evidence was here the niche data whereas experience is holistic and considered the broad context, potentially inverting traditional ways of thinking about the nomothetic – idiographic debate. Though service users felt their contribution was vital in developing a tool with multiple applications, they added that the generalisability of scientific evidence remained an important consideration:

'[Charity name] may have got a lot of calls saying [medication name] doesn't work for them but there might be thousands of people out there for whom it does work who haven't bothered to call. So you know I am inclined to um, um you know believe that there are, that there's a certain rigour about science'. (Evan).

Dedication to developing the best product, even if it was not composed solely of service user points of view was widely recognised. Though the aim was for the 'best guideline', the details of this vision were not the same for everybody:

'There is still that sense that everyone wants to do the best we can with it, the difficulty is with it, what is everyone's idea of a guideline is slightly different, what I would view as the best guideline is different to what other people would view as the best guideline' (Beth).

3.5.4. Around the Table: Inclusion and Exclusion can Co-occur

Service users often tried hard to contribute; features of the group deliberation mechanism sometimes allowed and sometimes prevented these attempts from having their maximum impact. This was due partly to the rigidity of the process and partly to the complexity of the information being discussed. Beth highlighted the paradox in being invited to do a job, for which the tools were non-existent or inappropriate:

'Sometimes it feels that you put a point of view from experience and they come back at you and say 'That's not what the research shows' and I'm thinking like well that's not what my contribution is about, but they'll dismiss that because of their research and I wonder, I've wondered about that sometimes, well what's the point of me being here if that's what you are going to do...but on the whole its quite positive'.

An in-vivo code (a term that repeatedly occurred in interviews and became endowed with a particular meaning in the analysis, Charmaz 2003) emerged: 'around the table':

'Myself, myself and the other service users had gone through the life and had the experience and could tell people around the table what might happen or what had happened' (Joe).

Despite acknowledged differences in power between group members, this term was reminiscent of the round table of Arthurian legend that demonstrated equality between knights. This may be reconciled by another idea in this section that attendees had a common aim. There was a sense of a respect for the different expertise people brought to the team that was respected and capitalised upon:

'Well actually they were bringing their experience they'd had, their professional experience so in that way they all had something to give and were coming at it from a different angle'.

The mechanisms by which people were made to feel included were both practical and interpersonal. Most respondents described a slot for ‘user and carer concerns’ being included on the agenda:

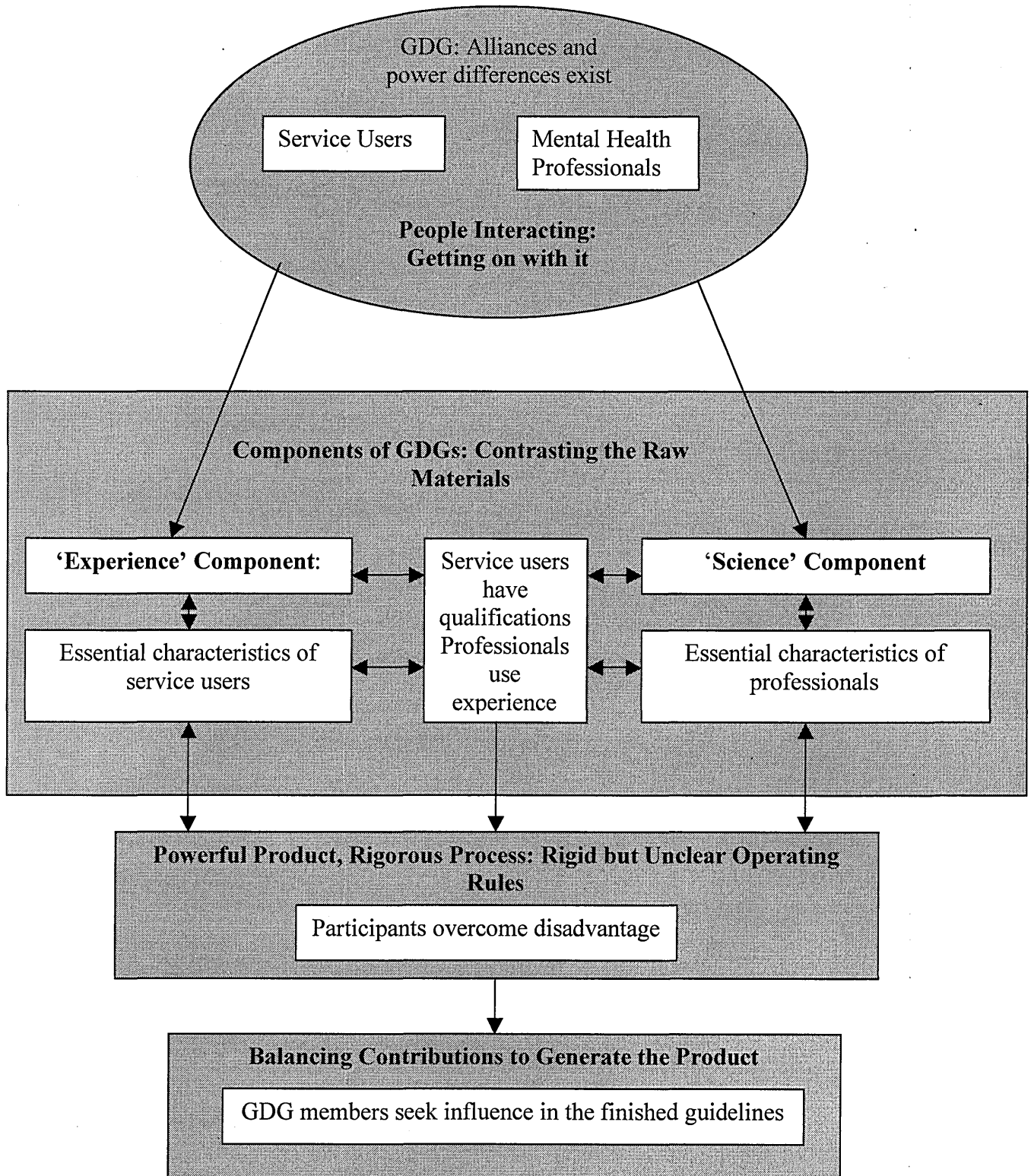
‘There was a formal space made in the structure of the day for us to talk and we, we changed the position of that, initially it was early on in the, in the proceedings and I think I suggested that it came later so, as it was hard to know what you thought about something when you hadn’t actually had the day’ (Leah).

Though the system had such inbuilt mechanisms for ensuring service users could comment on the process, there were times when these were insufficient and when service users wanted to comment in a more ad hoc way. This did not compromise the rigidity of the system and user views tended to be welcomed. GDG chairpersons received praise for their vigilance and persistence in making space for comments when he/she noticed that a service user had something to say on a topic ‘outside’ the agenda item.

‘And the chair was very good, he was watching out for us, to make sure, so to let us have space to think’. (Christine).

The value of viewing the guideline development process as akin to the development of machinery or tools is in allowing the process and product to be assessed independently. The people involved take different roles throughout the description, in representing, deliberating and comprising data, and acting as components, inventors, designers and cynics. The roles people assumed were neither simple nor mutually exclusive and the team represented a wealth of expertise and skill. Though some less positive experiences and reflections were apparent, everybody had gained from or contributed something valuable to the process and the tool was widely regarded as the product of a group of people working together as a finely tuned and sensitive yet robust machine. The associations between the categories described above are represented in diagrammatic form (figure 1).

Figure 1 User Involvement in NICE Guidelines:
A Machine Development Analogy



4. Discussion

4.1. Summary

Though the above results were presented as categories, these are not wholly discrete entities; there are many points at which they overlap. A range of answers to the question ‘what are service users’ perceptions of their involvement in NICE mental health guidelines?’ emerged from the data. Traditional conceptions of service user experience being idiosyncratic and research evidence being widely applicable have been challenged. Collaboration between service users and professionals is possible but not assured – both sides have to invest energy in the process. Service users should not wait to be given influence but must assert it. Power differences can hinder the process so criteria for success in effective collaboration include open-minded professionals and experienced service users. Though many of the findings in Jarrett’s (2004) survey were replicated, other criticisms of user involvement were not upheld. Service users can find meaningful ways to contribute and are not unaware of the value of science. They do not always rely solely on their personal experience but draw on a range of sources. They have practiced ways of balancing the two entities (science and experience), and found that they might be integrated by one filling the gaps in the other. Service users often have relevant qualifications and both professionals’ and users’ experience can illuminate guidelines. Service users identify with the guideline development process and the recommendations made. They may feel confident in trusting professionals’ judgment on areas they find inaccessible and find ways to compensate for this or to flag up their displeasure. Service users’ and professionals’ experience acts as an effective tool for analyzing data rather than being a form of evidence in itself.

4.2. Use of the Metaphor

The metaphor of designing a machine was used to convey the idea of a group coming together to craft a product for public consumption. This product (guidelines) needed to be of high quality, but had to incorporate a wide range of people’s perspectives. The

metaphor acted as a vehicle for communicating the richness of the findings. As the metaphor itself is not amenable to being supported by evidence, this discussion focus on theory and research links to specific findings.

4.3. Discussion of Findings

4.3.1. People Interacting: Getting on with it

Between the GDG and the 'product' were stages of contrasting evidence and experience and overcoming process-related disadvantages. The multi-disciplinary team was observed by and participated in by interviewees. Alliances and power differentials were noted. Team members – the designers and manufacturers of the product did not automatically find harmony in their interactions, but found a way to get on with each other and to get on with the task. Service users perceived that they and professionals constitute different groups within the team, and noticed the dynamics that reinforce differences or aid collaboration between groups. Service users may believe they are viewed as a lower status group than mental health professionals, given the sometimes involuntary nature of their contact (Tropp 2006). Social skills were described by participants as important. Attempts by professionals to show equality and interest (e.g. informal conversations) were noted, however where service users anticipate inequality, a history of subjugation may mean some attempts at communication were experienced negatively, in highlighting differences, perhaps as they disconfirm an individual's expectations ('selective abstraction', Beck 1995 p119).

Interaction occurred between and within sub-groups in GDGs (e.g. service users and psychologists). The intergroup alliance described by Steve may demonstrate his and the psychologist's interest in valuing diversity. Tropp and Bianchi (2006) described research which found that those 'out-group' members (service users) who saw 'in-group' members (psychologists) as viewing diversity positively were more likely to be interested in intergroup contact, and may be more inclined to report it; valuing diversity may then increase its profile. The differences in perceptions of psychologists (e.g. being like

psychiatrists or good at involvement) highlight variability in training, orientation to particular models and personality and reinforce that psychologists are human and as such exhibit individual differences. Parker (2007) accused psychologists of aspiring to equality with psychiatrists, a position which gained some support. Psychologists were seen as more likely to promote user involvement and make use of users' contributions. This supports findings by Soffe *et al.* (2004) that clinical psychologists' views of user involvement are generally positive and suggests that the BPS's entreaties for clinical psychologists to value service users as 'equal partners' (BPS 2001 p2) are enjoying some success. Psychologists may then be well placed to initiate user involvement in GDGs.

Participants reported having to engage with the process on NICE's terms. This included allowing the dominance of the RCT. Contrary to van Wersch and Eccles' (2001) finding that service users do not value science, interviewees obviously appreciated such expertise. Many reported that perhaps the ability and knowledge that professional training brings should be foregrounded over user experience, though this is possibly contentious among activists. NICE is a political body, having a powerful advisory role in treatment decisions. Daniels and Sabin (2002) describe the optimal process of making decisions about allocating health resources as employing a fair and legitimate procedure; even where the outcome is not what a particular individual would choose, the process at which is was reached is seen as inclusive, thus reasonable. Daniels and Sabin (2002) term this 'deliberative democracy' (p58). They add that part of this is 'to accept rules of the game – or sometimes seek rule changes – that promote the game's essential skills' (p44). This suggestion undermines the plea made by Stickley (2006) for service users to achieve emancipation rather than work on the terms of the majority, though service users acted to change rules that diminished their involvement, the RCT's supremacy remains assured.

Psychiatrists were seen as leaders, psychologists less so. George Orwell's *Animal farm* (1945) was previously mentioned but this was not intended to imply that features of GDGs other than the statement about 'equality' were synonymous with Orwell's vision of communism. People were not surprised by psychiatrists' dominance and some felt it was deserved. In *Animal Farm*, the dream of equality between animals is lost and one pig

becomes a terrifying figurehead. This analogy was not meant to suggest that psychiatrists' dominance is dictatorial, but given the historical context, absolute equality - though perhaps hoped for, was unlikely. Psychologists may be well placed to employ knowledge of power relations and group processes to prevent conflict and resentment from hindering deliberations. They may be viewed differently to other professions because of their exclusion from the formal admission of clients, and the collaborative nature of their relationships with service users. The BPS (2001) outlines that clinical psychologists should 'enhance [service users'] sense of self-understanding, self-respect and self-worth' (p2). These skills are likely to increase service users' satisfaction with their relationship with services.

4.3.2. Components of GDGs: Contrasting the Raw Materials

Components included the different types of evidence and the characteristics of those championing them. Experience and science overlapped and their influence in the final product was moderated by GDG members acting as 'experts by profession' or 'experts by experience'.

4.3.2.1. Experts by Experience

Some people found personal details of experience were more explicitly requested than others. One participant experienced the lack of 'probing' about her experience as caring. Having to assert experience perhaps means individuals can select when they interject and how much information to give. This perhaps reverses the consulting room dynamic whereby the client is continually assessed and often repeats similar information, perhaps leading to what Tarrrier *et al.* (2002) term 'assessment fatigue' (p370). Systemic psychological theories, such as solution-focused ideas represent a move away from problem-saturated accounts (Dallos and Draper 2005) and focus more on exceptions and successes. This positive outlook means psychologists may be gainfully employed in helping build stories of success in GDGs as well as in individuals' lives.

Participants often predicted that 'human' factors would not feature greatly in the guidelines. Service user experience and qualitative research are not synonymous but are often related. Psychologists train in qualitative and quantitative methodologies and as such may be able to critique both positions. Several participants highlighted the unique perspective that service users have, that is only learnt through personal experience. A 'failsafe' mechanism seemed to be provided by service users, which prevented professionals from using heuristics or other shortcuts that may not respect the positions different groups hold in society. Robert *et al.* (2003) suggest user involvement can be used in this way, to challenge taken-for-granted assumptions. As such, service users may affect the tone or context of a guideline even where specific recommendations are not directly linked to their input. This holistic viewpoint has been recognised by others, e.g. Thornicroft *et al.* (2002) who write of service users' interest in the whole person as opposed to other approaches, such as the medical model. Psychologists aim to reflect on the service user's context and should be aware of issues of power and diversity (BPS 1995).

The idea of users' contributions not being solely 'personal' but drawing on various sources challenges views about service users' experience being unrepresentative and idiosyncratic. Where individuals are drawing on the experiences of others, they may display cognitive distortions (Beck 1995) in attending to and reporting information that confirms their own beliefs, this also applies to mental health professionals (Sladeczek *et al.* 2006). However, allusions to the heterogeneity of the experience of distress again undermines the accusation that personal experience is niche and only research evidence is broad and generalisable. Service user experience may become expertise, by individuals comparing their experience with that of their peers and processing events with time.

Service users' presence may increase transparency and credibility where decisions that ration resources are made, by increasing the number of options considered (Daniels and Sabin 2002). For some, being involved gave credibility to guidelines. Daniels and Sabin disagree that service user participation in decisions that restrict access to health services (e.g. NICE guidelines) increases what they term 'legitimacy' (p4), as service users are not

given to shadowy operators ‘in control’ of the GDG machine. The antithesis of this model is the non-constant sum theory, that power is generated within individuals and is effectively limitless. This lends itself more readily to the emancipation of service users (Stickley 2006).

The benefits of the current NICE approach to developing guidelines over other consensus methods (such as NGT and the Delphi Method) include group members having greater influence over topics they have more expertise in. For example, pharmacologists might appropriately have more impact on decisions concerning medication. This applies to service users also – having greater authority over appropriate treatment goals makes good use of their expertise. The advantages of meetings over questionnaires being circulated increase deliberative justice (keeping a watchful eye on the ingredients of debate), making decisions more quickly and people spontaneously generating ideas that may not occur to them in isolation. As such the advantages of other methods (such as shared ‘airtime’) may not allow some of the unique factors that expedite involvement in the NICE method to be replicated.

4.3.4. Balancing Contributions to Generate the Product

The purpose of the process is to develop a guideline, a product of the components described so far. As is evident, many factors influence the journey from GDG meeting to finished product and members had to work hard to find an appropriate combination of science and experience.

4.3.4.1. Service Users’ Satisfaction with the Process: Producing Justice

In contrast with deliberative justice (a fair or legitimate process – aided by service user presence), Daniels and Sabin (2002) discuss ‘distributive justice’ (p 169). This refers to the outcomes of resource allocation decisions - effectively stating who gets what in the health system. Daniels and Sabin argue that these decisions (here NICE guidelines themselves) may not agree with the wishes of the service user (or other group members)

but may still be seen to be 'reasonable' if deliberative justice has been applied. If individuals are aware of the ingredients of a decision they are more likely to see any outcome as arrived at fairly. NICE's policies on social value judgements adopt these principles under the terms 'distributive' and 'procedural' justice (NICE 2005 p12-13). This is supported by some participants in the present research who stated that they had benefited from the process despite disagreeing with the outcome. The corollary, participants not agreeing with the 'ingredients' of a decision (for example the reliance on RCTs) was also reported, though no satisfactory solution was apparent. Service users may influence the guidelines in other ways but where both product and process are contested drastic action may be taken. Pacitti (2005) reports an example where the service users on his guidelines resigned on principle.

4.3.4.2. Finding a Balance between different Perspectives and Discourses

Language, particularly the use of jargon often impedes service user involvement (van Wersch and Eccles 2001) by making discussions inaccessible. Foucault (1980) suggests that power may be expressed through language that then defines and perpetuates the different roles people assume within society. Language may reinforce stereotypes or exclude people not possessing the appropriate vocabulary. Others' fluency did not have to present a barrier - languages could be learned or it could be made clear that ambiguous terms require clarification. Both of these solutions involved highlighting service users' disadvantage, through giving explanations or by the individual having to conform to the dominant discourse by learning it him- or her- self.

Where topics eluded understanding, some participants felt able to trust professionals to make decisions on their behalf. Rhodes and Nocon (1998) suggest that there exists an 'authority of health professionals to speak on their [service users'] behalf', implying service users do not contribute anything new. Service users may relinquish control over decisions to professionals, sometimes acknowledging that they do not have the appropriate expertise (Hickey and Kipping 1998). Research has found that 24% of service users with schizophrenia trusted their prescribing professionals to make treatment

choices even when no information about the intervention was given (Paton and Esop 2005). Psychologists may be inclined to signal their discomfort with this situation given the emphasis on informed consent in their code of conduct (BPS 1995).

Interviewees had both positive and negative reflections on decision-making within GDGs. The sheer range of professions represented in groups meant there were likely to be several visions of the 'best guideline', and reports suggested that the process of deciding what it should look like was not formalised from the beginning. The potential for implementing a voting process was raised. Sabin and Daniels (2002) report difficulties with this approach, in that the minority can be forced to capitulate to the majority even when there is 'fundamental moral disagreement' (p35), which has occurred within GDGs (e.g. Pacitti 2005).

Conflict was an inevitable part of the deliberative process. It may be seen as a sign of equality that service users were as subject to people's irritations as others. The examples given seemed to suggest that some participants struggled to move from being seen as 'patient'. Peck *et al.* (2002) describe the government (in the context of Department of Health proposals) as 'clearly viewing the service user as patient rather than as consumer or survivor' (p448). This discussion has mentioned service users requiring certain types of experience to be accepted as successful GDG members. The message seems to be that though the 'lunatics cannot run the asylum'; appropriately experienced service users may usefully contribute to its board of directors though again this is not on the service user's terms.

The epistemologies referred to earlier (positivism and phenomenology) did not appear, in practice, to be diametrically opposed, and may have been reconciled. Service users valued the solidity of science, and professionals using personal experience showed some overlap. Willig (2001 p3) supports this finding by stating that in practice, even scientists are rarely 'unreconstructed positivists' given their recognition of the selective nature of observation. The progression of knowledge from thesis to antithesis to synthesis (Jasanoff 2003) may be apparent in this account – medical and psychological treatments

may have moved from one extreme position to the other and be reaching a point where both are valued in the middle. Mechanisms whereby the two epistemologies co-existed or complemented each other are described elsewhere in this discussion. Because of the extent of resources available for this thesis further exploration of this notion was not possible.

4.4. Conclusion

At this point it is useful to bring these concepts together. The categories found included interpersonal, epistemological and process-related elements. These are related to Moreira *et al.*'s (2006) four domains of reasoning ('science'; 'practice'; 'politics' and 'process' / 'boundaries'). 'Science' was an important ingredient. All participants were concerned about standards of care, with RCTs acknowledged as sometimes being an appropriate way of assessing them. Ways of implementing recommendations into 'practice' (good practice points illustrated by testimonials) were for some appropriate vehicles for user views and for others unverifiable. Politics were apparent in group alliances, and in the occasional overruling of recommendations, much to participants' dismay; though it may be Political pressures that mean service users are included at all. Politics may also relate to user expertise rather than experience being the currency of debate. Finally 'process' and 'boundaries' were significant, boundaries were porous with service users using science and professionals citing experience, similarly the process of decision-making was opaque and not planned yet formal. The audience (another factor in Moreira *et al.*'s account) was considered in terms of making things comprehensive for the lay reader, as efforts were made to use experience to bridge the gap between science and understanding by explaining the terminology used.

Service users have had to overcome barriers to involvement, but with supportive policies and professionals their endeavours are often encouraged, if on the terms of the 'service'. Although science is appropriately viewed as evidence, experience may be more usefully viewed as a particular, unique form of judgement used to interpret evidence than as data of itself. Beresford and Branfield (2006) reported a project considering user-defined

outcomes as requiring more intense work over a longer time frame than anticipated, suggesting that involvement might increase time pressure and make reaching consensus harder. Involvement may be difficult and means that service users must balance assertiveness and conforming to appropriate mores, but it remains worthwhile. Coleman and Harding (2004)'s discussion of partnership perhaps applies – that it may be difficult or even impossible, but should not be lost as a goal. Despite including service users on GDGs being harder than excluding them, their perspective is a useful 'reality test'.

4.4.1. Implications for Psychologists

The professional skills of the psychologist in developing an alliance; research; communication and managing power imbalances mean they are potentially useful members of GDGs, both academically and interpersonally. It is unfortunate that this potential may not always seem to be fulfilled, in the eyes of service users. However where psychologists' involvement skills were sometimes viewed positively. The difficulties participants described in distinguishing psychologists from other professionals was surprising, and suggests a need for the profession to assert its individuality. The involvement of psychologists in NICE guidelines may help to raise their profile, particularly relevant given the impact of recommendations concerning talking treatments (Eg in offering family interventions in psychosis, NICE 2002).

4.4.2. Recommendations

The findings of the research were presented to representatives of NICE's mental health guideline unit and the following recommendations were made:

1. Qualitative methodology receiving the attention outlined by NICE
2. The initial consultation period to be extended to allow for service user views to be elicited and included in the scope
3. A glossary of technical terms to be developed and disseminated at the start of the guideline development process

4. Selecting members (both service users and professionals) with appropriate skills (personal and professional)

It is unclear at this stage if any of these recommendations will be addressed as a response to the study but at the time of writing, two potentially complementary changes are underway. Consultation on a manual standardising deliberating processes has begun, and NICE standing committees are being made open to the public to increase transparency. This may increase deliberative (procedural) justice as emphasized by Daniels and Sabin (2002).

4.4.3. Limitations

As the research was qualitative, the results are transferable but not generalisable beyond the context that participants were speaking from. This means findings may apply to similar GDGs but may not be used to explain phenomena in other populations or situations. Other group members might have very similar experiences to service users in finding the systematic review methodology difficult to understand and the pressure to contribute in a certain way anxiety-provoking. It is not possible therefore to state whether the perceptions participants reported were unique to service users. The practical limitations of this study include not reaching saturation (a point where no new threads emerge from transcriptions) though movement towards this point was evident. Not arriving at this position means that theory generation is problematised as some elements may not have been captured. The sample was composed entirely of white British adults, again potentially influencing people's experience of inclusion and discrimination.

Though participants were self-selecting and possibly 'unrepresentative', (a problem for quantitative researchers who prefer 'randomisation' that attenuates the unique features of the sample), this is not insurmountable if the findings are not generalised to other populations (see above). The interviewer (researcher) introduced herself as both a service user and a psychologist, which perhaps made it difficult for interviewees to situate and relate to her across the service user-professional / positivism - phenomenology divide. A

related difficulty concerns the researcher's prior experience of and feelings about the process being studied. This is an unavoidable part of any research however, as people do not often expend effort on topics they are not interested in. Additionally the perspective and role of the psychologist was not fully explored.

A paradoxical limitation is the lack of user involvement in the research design, data collection and analysis procedures. Though the conclusions were fed back to and presented to service users, Telford and Faulkener (2004) outline that this is insufficient if research is to embody true involvement. The research question emerged from service users asking what user involvement in this context looked like and the researcher is a former service user, but the lack of external or practical user involvement is unfortunate.

4.4.4. Future Research

Future research could usefully take an ethnographic stance and analyse GDG meetings themselves. Transcripts may reveal power differences, alliances and other phenomena that participants are currently not aware of. Interviewing other members of GDGs could also reveal more about the interplay between different groups (e.g. carers, psychiatrists, service users and psychologists). Using both techniques together (analysing the discourse from a GDG and interviewing participants about it afterwards) may highlight the different perspectives people take and the assumptions these engender. Examining other professions' experience may illuminate some of the findings reported here, particularly whether they are unique to the service users interviewed. It would also be interesting to investigate the similarities and differences between service user and carer experiences, and to further explore the role of the psychologist as clinician; academic; role model; facilitator and researcher.

'It is a matter of contestable judgement as to what people need'

(O'Keefe and Hogg 1999, p251)

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Appendix A

Surrey University Ethics Coversheet



Ethics Committee

**Submission To The University's School of Human Sciences Committee For The Approval Of Study Protocol
Cover Sheet**

1. Title of project: Optimising Mental Health Professionals' and Service Users and Carers' Involvement in NICE Guideline Development: The Roles of Evidence and Experience.

Names of Principal Investigators	Qualifications	Department/Institution
<i>Please note that supervisors must be listed as Principal Investigators in submissions from all researchers who are registered as students of the University.</i>		
Emma Harding	BSc (hons), MSc.	School of Psychology
Mark Hayward	BA (hons), D Clin Psy	School of Psychology
Dora Brown	BSc (hons), PhD.	School of Psychology
Catherine Pettinari	BA (hons), MA, PhD.	College Research Unit, Royal College of Psychiatrists
Names of Co-Investigators		Department/Degree Course

3. Signature of Supervisor (where appropriate) to indicate that (s)he has read and approved the protocol submission:

Date:

1/5/07

4. Details of Other Collaborators:

N/A

5. Details of Sponsors:

None

6. Details of payments to Investigators, Departments, Schools or Institutions. Investigators who receive payment as part of an annual consultancy fee should advise the Committee of the situation:

None

7. Where will the project be carried out ? (e.g. University, hospital, etc.):

Interviews will be held in a room at the Royal College of Psychiatrists' College Research Unit (CRU) unless the individual expresses another preference

8. Source of the participants to be studied:

These will be people who have recently contributed to NICE Guidelines on mental health related disorders (service users, carers, psychologists and psychiatrists). These will be identified by the CRU's project manager who will forward each potential participant a letter to which they can respond if they are interested in participating.

9. Details of payments to participants:

I will reimburse reasonable expenses (ie. From within London or the surrounding area) from my research budget, or my personal finances if required.

10. Investigators are asked to note that research proposals involving the following must be submitted to an NHS Research Ethics Committee for ethical review. Please indicate which of the categories below, if any, applies to your research, and provide details of your NHS REC application. The Ethics Committee will not consider research proposals which meet any of these criteria until NHS REC approval has been obtained.

- a. patients and users of the NHS. This includes all potential research participants recruited by virtue of the patient or user's past or present treatment by, or use of, the NHS. It includes NHS patients treated under contract with private sector institutions.
- b. individuals identified as potential research participants because of their status as relatives or carers of patients and users of the NHS, as defined above.
- c. access to data, organs or other bodily material of past and present NHS patients.
- d. fetal material and IVF involving NHS patients.
- e. the recently dead in NHS premises.
- f. the use of, or potential access to, NHS premises or facilities.
- g. NHS staff – recruited as research participants by virtue of their professional role.

NB: I have enclosed a document from COREC regarding my research proposal

11. Has a risk assessment been carried out in respect of this research, either for potential participants or the researchers? If yes, please attach a summary document of the issues considered. If no, please explain why it has not been done.

No risk assessment has been undertaken as no treatment is involved and participants will not be required to discuss their mental distress or life events.

17. Checklist of Accompanying Documents (Please tick the appropriate boxes)

Please ensure that, where appropriate, the following documents are submitted along with your application:	
i	A summary of the project, (approximately 500 words), including its principal aims and objectives ; this should provide a clear description of who is doing what, to whom, to how many, where, when and why in non-technical, lay terms <input checked="" type="checkbox"/>
ii	The detailed protocol for the project <input checked="" type="checkbox"/>
iii	Evidence of agreement of other collaborators <input checked="" type="checkbox"/>
iv	Copy of the Information Sheet for participants <input checked="" type="checkbox"/>
v	Copy of the Consent Form <input checked="" type="checkbox"/>
vi	Copy of questionnaire/Interview Schedule <input checked="" type="checkbox"/>
vii	Copies of standard letters related to the project <input checked="" type="checkbox"/>
viii	Copy of risk assessment <input type="checkbox"/>
ix	Protocol Submission Proforma: Insurance <input type="checkbox"/>
x	Confirmation that CRB (Criminal Records Bureau) checks have been carried out – this will be required if there is contact with children and vulnerable adults for significant periods of time <input type="checkbox"/>
xi	Evidence of insurance cover/indemnity, particularly for drugs trials (Please refer to the Insurance Guidelines) <input type="checkbox"/>
xii	Copy of the Clinical Trials Exemption Certificate or Product Licence Number <input type="checkbox"/>
xiii	Information concerning any other Ethical Committee to which an application for approval is being made <input checked="" type="checkbox"/>
xiv	Letter of notification of NHS approval <input type="checkbox"/>

18. Names and signatures of all Investigators:

M. T. Pugh *Wattman*
J. B. ... *Harding*

19. Date of Application:

1/5/07

Appendix B

Proposal to Surrey University

N.B. The focus of the research design changed when enough interest was gained from service users to enable their perspective to be fully explored. Therefore other populations (e.g. psychiatrists and carers) were excluded.

Detailed Protocol

Optimising Mental Health Professionals' and Service Users' and Carers' Involvement in NICE Guideline Development: the Roles of Evidence and Experience

Background: The Department of Health is increasingly calling for patient (service user)⁵ involvement in the development of mental health services (e.g. Department of Health 2005). Evidence-based practice is also key to delivering such services, the 'gold standard' being developing guidelines in groups that include service users and carers who contribute from personal experience (Kelson 2002). However, reconciling the importance of scientific evidence with the value of service user experience is something that mental health professionals are sometimes sceptical of (eg. Summers 2003, Soffe *et al.* 2004). Coulter (in Anderson *et al.* 2006) states that so far patient involvement has not looked at the quality of interactions between individual clinicians and patients. Clinical psychologists are arguably well placed to develop collaborative relationships with service users and carers (Hayward and Harding 2006) given the individualistic focus of formulation (Tarrrier 2006).

Service users have often felt disempowered by mental health professionals as well as the rest of society (Chamberlin and Rogers 1990). Psychological theories of minority influence (eg. Festinger 1950), intergroup relations (eg. Tajfel 1978) and group behaviour (eg. McGrath 1984) attempt to explain how disempowered individuals contribute to and influence decision-making processes. The Bristol Theory (Tajfel 1978) posits that intergroup relations are comprised of 4 elements – categorization (to provide order), identity (with the group), comparisons (between groups) and positive distinctiveness (*vis à vis* other groups). Therefore service users and mental health professionals may see themselves as very different, and interact from positions of differing power.

Experience may be constructed in a 'relativist' way (namely that reality is accessible only through individuals' representations of the world (Burr 2003). In contrast, scientific research, based on 'experiment and observation' is of the 'positivist' tradition and was

⁵ I will use the terms 'patient' and 'service user' interchangeably as different agencies often have preferences for one label over another, when referring to people with mental health problems.

widely viewed by academics as the best way 'to obtain reliable knowledge about the world' for much of the last century (quotations from Machamer 2002 p2). Epistemology, the study of knowledge has a role to play in assessing the relative contributions of 'pure' science and more experience-based philosophies. To explore this 'balance' I intend to utilise the social constructionist notion of critiquing 'taken for granted knowledge' (Burr 2003). This may help optimise service user involvement in service development by emphasising the benefits of exploring previously polarized views of 'evidence'.

The National Institute of Clinical Excellence (NICE) commissions guidelines for the treatment of mental health problems. Producing such guidelines involves clinical psychologists and mental health service users. These guidelines have been instrumental in emphasising the role of psychological therapies in managing disorders such as schizophrenia (NICE 2002) hence the relevance to clinical psychologists is great. Though attitudes towards service user involvement have been audited eg. (Summers 2003, Soffe *et al.* 2004), little theory exists about the relevant qualities mental health professionals possess. Further not enough exploration of how these qualities complement or constrain the types of evidence (science versus experience) has been undertaken. Investigating this may optimise service user and carer involvement in the face of criticisms of psychology as a 'pseudoscience' (Machamer 2002). In order to do this properly, it is important to investigate mental health professionals other than psychologists to provide a comparison. I have chosen psychiatrists, as they require significant postgraduate training. They are also likely to be represented within each GDG. It must be bourn in mind however that psychiatrists are perhaps the most powerful mental health professional (Thomas and Bracken 2004).

Objectives: To explore the values ascribed to service user experience alongside those given to scientific evidence in the development of NICE guidelines for mental health disorders. I will investigate two areas –firstly I will explore the ways the values of experience and evidence are reconciled. It must be recognised that I have been involved as a service user representative in the NICE guideline development process therefore must acknowledge my position as stakeholder. This may not be a disadvantage as the

research is qualitative rather than quantitative. In the light of this, After Whitley and Crawford (2005) I will aim to see myself as the 'lay person' and the informant as the 'expert' in my endeavour to understand the complex dynamic between different incarnations of 'mental health professional'. As such we (respondents and myself) will become co-participants in the research which will to some extent be an important replication of the phenomenon I am going to study – so being aware of my position and biases is an ethical and methodological imperative. Whitley and Crawford list some 'checks and balances' such as 'respondent validation' and 'multiple coding' that can help decrease the likelihood of researcher bias - which I will adopt where possible.

Secondly I hope to develop an understanding of the criteria that maximise the psychologist's contribution to expediting and valuing service user experience. Given the focus on individuals' heterogeneity in psychological theory, therapeutic approaches and training (eg. Wallach and Wallach 1983 cited in Lacey and Schwartz 1996). Psychologists ideally balance individual approaches with a contrasting appreciation of evidence-based practice, rendering them in a unique position to comment. For example, formulation- a cornerstone of clinical psychology (Crellin 1998) - has been described as 'translating theory into therapy', therapy presumably being an individualised activity. Persons (2006) describes the specific means by which therapists use nomothetic research evidence to inform idiographic case formulations.

Research Question: As the approach utilises Grounded Theory (GT – see below) there are no specific *a priori* assumptions. However the research question may be articulated as follows 'how can the ostensibly competing values of scientific evidence and 'expertise by experience' be reconciled, if at all, and which qualities do psychologists possess that contribute to optimising service user involvement in these terms?

Criteria for Inclusion / Exclusion of Participants: Inclusion criteria will be that the individual is willing to volunteer and is either a service user or carer, psychiatrist or psychologist that has contributed to a mental health related disorder NICE guideline that

has been completed, or is close to completion (ie a first draft has been written). Exclusion criteria are that the guideline is not near completion and / or the individual is from a background not stipulated in the inclusion criteria listed above. I aim to balance the numbers of people from each background so they are approximately equal.

The 'theoretical sample' will be 'evolving' – that is the next interviewee will be determined following analysis of the previous one. This will involve following up important issues and investigating each rigorously. I will commence this process by interviewing one person from each 'population' – a service user, a carer, a psychologist and a psychiatrist. I aim to balance the numbers of people from each background so they are approximately equal and envisage that there will be up to 12 interviews.

Psychologists, psychiatrists and service users who were involved in the development of NICE guidelines published through the Mental Health Collaborating Centre will be accessible to interview. Nine such guidelines have been published to date, four in the past year. A further three are ongoing and expected to be published before July 2007.

Experimental Design: I plan to use a qualitative design and analyse interview data using Grounded Theory (GT; Glaser and Strauss 1967). A letter (enclosed) will be distributed to Guideline Development Group (GDG) members who are eligible to participate. This will be sent by the NICE guideline project manager for the National Collaborating Centre for Mental Health who co-ordinate NICE guidelines. Postage will be paid from the principal researcher's research budget or own funds. This letter will invite people to contact the principle researcher if they are interested in finding out more or getting involved. This will be facilitated by returning a slip enclosed in the aforementioned letter (again postage will be paid as mentioned above). After completing consent forms (enclosed), an initial sample of four people will be interviewed using a semi-structured interview protocol (enclosed).

The semi-structured interview protocol draws on 'sensitizing concepts' (Blumer 1969 cited in Charmaz, in Smith 2003) highlighted in previous literature (eg. Summers 2003,

Taylor 2000). These data will be transcribed and analysed for emerging theoretical categories (Glaser 1978 cited in Charmaz, in Smith 2003) which will be coded as they develop. This coding will be line-by-line then larger clusters of themes that explain wider issues in the data (conceptual categories after Charmaz, in Smith 2003) will be noted. Focused coding (Charmaz, In Smith 2003), that is 'comparing data, incidents, contexts and concepts' (p101) will lead to 'memo-writing' – defining the analytic aspects, processes and comparisons of categories and codes and listing the 'raw data' they subsume as well as proposing links to existing research. Initial data will continually be reanalysed in the light of these new groupings to inform this process. Theoretical sampling will be employed to investigate emergent links, codes and categories. This is the method recommended by Glaser and Strauss (1967, cited in Charmaz in Smith 2003), the researchers who developed GT. I feel that it is the most appropriate approach. Theoretical sampling means that on the basis of the initial analysis, further participants will be interviewed and the resultant transcriptions will add to the entire process. In practice, the analyses of the first interviews will highlight issues that I will rigorously seek to elucidate by selecting the next interviewee based on their capacity to expand upon said issues. Memos will be refined and synthesised to underpin the account that emerges from the iterative data collection, analysis, collection and reanalysis process. In the time frame available, it is not likely that 'saturation' will be achieved. 'Saturation' refers to the point where no new ideas issues or opinions are being generated. However the analysis will be thorough in that issues that are raised will be rigorously explored. The process may necessitate transcribing individual Guideline Development Group meetings.

Ethical Considerations: There is the potential for participants to give 'socially desirable' responses based on the implication from myself, the Patient and Public Involvement Unit (PIU – the agency that oversees patient and public involvement in national guidelines and audits.) and NICE that service user involvement is useful, effective and required. However this is less of an issue in a qualitative study. This is because responses will be *interpreted* as such by the researcher and the reasons for and content of them can be considered in the reflection and discussion. Once guidelines are published it may be difficult for contributors to undermine them on a political level. It is

also possible that people may feel undermined by talking about their experience of and views on service user involvement in this context. I would ensure people were aware that I would offer support to them should they have any negative feelings. I am able to draw on experience of disclosing personal information to promote mental health in the media, which can bring up some similar feelings. Further I would reassure participants that responses would remain confidential and no-one would be identifiable from my doctoral thesis or any resultant publications. This requires that I do not disclose the specific guidelines I investigate.

As a service user and a stakeholder in a previous guideline development process I will come to the analysis with memories and biases, though being aware of these is a necessary prerequisite for the effective implementation of Grounded Theory (Charmaz in Smith 2003). I will ensure that people were given time to consider whether they wish to be involved and would advise them of the details including timeline of the data collection and analysis process. Thus their fully informed consent would be necessary before I interviewed any individual. I am also hoping to write the research up for publication and will make a summary of the findings known to participants as soon as the research has been written up for my thesis.

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Summers, A. (2003) Involving users in the development of mental health services: A study of psychiatrists' views. *Journal of Mental Health*. 12 (2) 161 – 174.

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Whitley, R. and Crawford, M. (2005). Qualitative research in psychiatry. *Canadian Journal of Psychiatry*, 50, 108 – 114.

Appendix C

Response from COREC

Send | Importance Normal | Options None | Close | Help

To:
Cc:
Bcc:
Subject: FW: Query re NICE research



Attachments:

> From: queries@corec.org.uk
> To: eemr42@hotmail.com
> Subject: RE: Query re NICE research
> Date: Wed, 28 Mar 2007 07:33:47 +0100
>
> Thank you.
> The following reply has been provided by Jo Downing, Information Officer
>
> Thank you for your query. The Research Governance Framework for Health and
> Social Care sets out the responsibilities and standards that apply to work
> managed within the formal research context. Under the Governance
> Arrangements for NHS Research Ethics Committees (GfREC), the main role of
> NHS RECs is to review research involving NHS patients. GfREC is available
> on our website at www.corec.org.uk/applicants/help/guidance.htm.
>
> Based on the information provided, we consider the study to be outside the
> remit of NHS RECs as it does not appear to involve the NHS. Therefore it
> does not require ethical review by a NHS Research Ethics Committee or
> approval from the NHS R&D office.
>

Emma Harding 2008
Volume I: Research Dossier

Microsoft Outlook Web Access

06/14/2008 11:58 PM

Send |  |  | Importance: Normal | Options: None | Close | Help

To:

Cc:

Bcc:

Subject: FW: Query re NICE research

Attachments:

- > Although ethical review by a NHS REC is not necessary in this case, all
- > types of study involving human participants should be conducted in
- > accordance with basic ethical principles such as informed consent and
- > respect for the confidentiality of participants. When processing
- > identifiable data there are also legal requirements under the Data
- > Protection Act 2000.
- >
- >
- > [Universities – You may wish to check whether the project could be reviewed
- > by the ethics committee within your own institution.]
- >
- > The above advice does not constitute a form of ethical approval but it may
- > be provided to a journal or other body as evidence that ethical approval is
- > not required under NHS research governance arrangements.
- >
- > However, if you feel that ethical review by a NHS REC is essential, please
- > write setting out your reasons and we will be pleased to consider further.
- >
- >
- >

Appendix D

Surrey University Ethics Approval



Dr Kate Davidson
Chair: SHS Ethics Committee
University of Surrey

Unis

University of
Surrey

School of
Human
Sciences

Guildford
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Facsimile:
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Emma Harding
Department of Psychology – PsychD
University of Surrey

29 May 2007

Dear Emma

Reference: 127-PSY-07
Optimising mental health professionals' and service users and carers' involvement in
NICE Guideline Development: The roles of evidence and experience

Thank you for your submission of the above proposal.

The School of Human Sciences Ethics Committee has given a favourable ethical opinion.

If there are any significant changes to this proposal you may need to consider requesting
scrutiny by the School Ethics Committee.

Yours sincerely

Kate Davidson

Dr Kate Davidson

Appendix E

Response from NICE About Ethical Approval

Windows Live Hotmail

http://bl104w.blu104.mail.live.com/mail/ReadMessageLight.aspx?...

Windows Live™ eemr42@hotmail.com Sign out

Home **Hotmail** Spaces OneCare MSN

New Reply Reply all Forward Delete Junk

Move to Options

RE: Ethics application

From: **Marcia Kelson** (Marcia.Kelson@nice.org.uk)
Sent: 08 May 2007 16:52:54
To: Emma Harding (eemr42@hotmail.com)

Dear Emma

Further to your email I can confirm that when you sought advice from the Patient and Public Involvement Programme at NICE, we advised that you approach COREC to determine if what ethical approval might be needed from them. I understand that COREC have let you know that ethical approval from them is not needed for your study, and on the further understanding that you are submitting your proposal for approval by your University ethics committee, this will satisfy NICE requirements.

Best wishes

Marcia


Dr. Marcia Kelson
Associate Director,
Patient and Public Involvement Programme
National Institute for Health and Clinical Excellence (NICE)
MidCity Place
71 High Holborn
London
WC1V 6NA

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Inbox
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Drafts
Sent
Deleted
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Dad
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jayjay
mates
media
Muriel
Surrey
Surrey Adv...
talks
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UEP

Manage folders

Today
Mail
Contacts
Calendar

So, what do you think? 

1 of 3

14/6/08 19:26

Appendix F

Letter to Participants



Faculty of
Arts and Human Sciences

Psychology
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F: +44 (0)1483 689553

www.surrey.ac.uk

Emma Harding
Trainee Clinical Psychologist
PsychD School of Psychology
University of Surrey
Guildford
Surrey GU2 7XH

August 2007

Dear Guideline Development Group member,

RE: Optimising Mental Health Professionals' and Service Users' and Carers' Involvement in NICE Guideline Development: the Roles of Evidence and Experience

I am a doctoral student at the University of Surrey, training as a clinical psychologist.

I am interested in researching the views of people who have recently contributed to the development of mental health disorder-related NICE guidelines. I am looking at the relative contributions of service user and carer experience and research / scientific evidence. My interest comes from my experience contributing to the first schizophrenia guidelines as a service user representative.

In order to do this, I am hoping to interview service users, carers, psychologists and psychiatrists who have recently been involved in such guidelines. Though the value of contributions of other professions is acknowledged they fall outside the remit of this preliminary research.



I estimate that interviews will take approximately 1 hour each. They will be held in a location convenient to you such as your home, workplace or an office in central London. I will be able to reimburse reasonable travel expenses. I envisage the interviews will be held in the Summer / Autumn of 2007. These interviews will be recorded to enable all comments to be included.

If you would be happy for me to contact you to provide some more information, with a view to being interviewed by myself, please return the enclosed slip using the stamped addressed envelope provided. I will then be in touch shortly after.

This research has received ethical approval and is conducted separately from NICE, the Patient and Public Involvement Programme and the National Collaborating Centre for Mental Health, though these bodies have been consulted and have given their consent for it to go ahead. Not participating will not affect your involvement with NICE in any way.

Your contribution would be greatly valued.

Yours sincerely,

Handwritten signature of Emma Harding.

Emma Harding, BSc. MSc.

REPLY SLIP

I (name) _____

Would be happy for Emma Harding, trainee clinical psychologist to contact me regarding her research into NICE guidelines.

My preferred method of contact is: (please delete as appropriate) telephone / letter

My contact details are: tel. no. _____

Address: _____

I am (please delete as appropriate) a service user / a carer / a psychologist / a psychiatrist
I was / am involved in the guidelines for _____

(please insert the name of the guideline you were working on).

-THANK YOU FOR YOUR ASSISTANCE-

Please use the stamped addressed envelope provided or send this slip to:

Emma Harding, Trainee Clinical Psychologist

PsychD, School of Psychology

University of Surrey

Guildford

Surrey GU2 7XH

Appendix G

Participant Information Sheet

Participant Information Sheet

Study title:

Optimising Mental Health Professionals' and Service Users' Involvement in NICE Guideline Development: the Roles of Evidence and Experience

Invitation paragraph:

You are being invited to participate in a research study. Before you decide whether you wish to take part it is important for you to understand why you have been asked, why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with friends, relatives and colleagues if you wish. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

This study aims to look at how service user and carer experience and research evidence are integrated when important decisions are made. In this case these decisions refer to those made in National Institute of Clinical Excellence (NICE) guidelines for mental health-related disorders.

Why have I been chosen?

I am interested in speaking to you as you are either a service user or carer, psychiatrist or psychologist who has been involved in a guideline development process. This means you may be able to look back over and describe the development process.

In total I will speak to approximately 12 people involved in guidelines.

What about other professions?

Though the importance of the contributions of professions such as nursing to guideline development are recognised, they are outside the remit of this preliminary research project.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are free to withhold any personal information or to withdraw at any time, without giving a reason. This will not affect your relationship with NICE, the Patient and Public

Involvement Programme (PIIP) or the National Collaborating Centre for Mental Health (NCCMH). Neither will a decision not to participate.

What would taking part entail?

I would invite you to be interviewed in your own home, workplace or at an office in central London.. The initial interview would last approximately 1 hour. This would involve answering some questions about your expectations and experience of being involved in the guideline development process. I may ask to talk to you again at a later date based on my analyses of yours' and others' data. I will reimburse reasonable travel expenses, to be discussed when arranging the interview(s). The interview(s) would be recorded to enable me to use as much detail as possible.

What are the advantages and disadvantages of taking part?

It is hoped you would be given the opportunity to express your views on user/ carer and research evidence involvement in the guideline development process. This would mean that we would be clearer about how different approaches were integrated in this nationally relevant process. This may influence other guideline development processes.

However it is possible that you may find that expressing your views on this subject is difficult if they are not all positive. They may conflict with the views others expressed during the process of guideline development or be critical of parts or all of the process of developing the guidelines. If you wished to talk to anybody about some of these feelings at any time one of the researchers would be available and you could choose whom you wished to talk to.

Confidentiality:

With regard to other guideline development group members, NICE, the PPIP and NCCMH

Though your interview would be tape recorded, your name would remain confidential. No-one other than the person you would be interviewed by would know what you had said. As such your comments would not be traceable to yourself. No other group members would be told that you were participating. The interviews would be held at your home, workplace or the National Collaborating Centre for Mental Health in central London, however other venues may be arranged. The recording and notes made from it would be kept under lock and key with access only available to the person who interviewed you and the supervisor of the research.

With regard to individual's care teams and colleagues

No information about participants will be fed back to those involved in their care / professional work. This includes their GP. Identifying information will be kept completely confidential.

With regard to writing about the study:

All information that is recorded or written during the course of interviews would be kept strictly confidential and stored securely. Only members of the research team would have access to these records. This information would be coded and have your name and other identifying details removed so that you would not be recognised from it. The study has been checked to ensure it complies with data protection laws.

What will happen to the results of the study?

The results of this study will be written-up for the principle researcher's doctoral thesis by July 2008. It will hopefully also be submitted to a national journal. You could receive feedback on the results of the study if you wanted to. No participant will be identified in any part of the write-up or article.

Who has reviewed the study?

The University of Surrey's school of human sciences ethics committee has reviewed and agreed to this research proposal. It was also submitted to COREC, the NHS' ethics review panel who felt that it did not require their consideration as it is not linked to the NHS. The PPIP, NICE, the NCCMH have also all reviewed and given consent for this research to proceed.

Any complaint or concerns about any aspects of the way you have been dealt with during the course of the study will be addressed; please contact Emma Harding, lead investigator at the PsychD course offices, on 01483 689441. If you would rather speak to someone else, please contact the research supervisor, Dr. Mark Hayward on the same number.

Contact for further information:

Emma Harding
Trainee Clinical Psychologist
PsychD, School of Psychology
University of Surrey
Guildford GU2 7XH
Tel: 01483 689441.

If you decide to participate in the study you will be given a copy of this information sheet and a signed consent form to keep.

Appendix H

Consent Form

CONSENT FORM

I the undersigned voluntarily agree to take part in the study on integrating experience and evidence in NICE guidelines on mental health related disorders.

I have read and understood the Information Sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been advised about any discomfort and possible ill-effects on my health and well-being which may result. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

I agree to comply with any instruction given to me during the study and to co-operate fully with the investigators. I shall inform them if I have any concern or complaint about the way I have been treated during the course of my involvement in this research.

I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the use of the results of the study on the understanding that my anonymity is preserved. I understand that no documents other than this will contain my name.

I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice.

I acknowledge that in consideration for completing the study I can expect my reasonable travel expenses to be reimbursed

I understand that in the event of my suffering a significant and enduring injury (including illness or disease) as a direct result of my participation in the study, compensation will be paid to me by the University, subject to certain provisos and limitations. The amount of compensation will be appropriate to the nature, severity and persistence of the injury and will, in general terms, be consistent with the amount of damages commonly awarded for similar injury by an English court in cases where the liability has been admitted

I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Name of volunteer (BLOCK CAPITALS)

Signed

Date

In the presence of (name of witness in BLOCK CAPITALS)

Signed

Date

Name of researcher/person taking consent (BLOCK CAPITALS)

Signed

Date

Appendix I

First Interview Schedule

Semi-structured Interview – Draft 3

Introduction

- Hello and thank you for your time
- Introduce myself – trainee, service user, carer, GDG member
- Check documents (consent form, participant info sheet)
- I am investigating people's views on guideline development
- Perspectives and relationships of/between service users / carers / psychologists / psychiatrists
- Length of interview – 1 hour
- Introduce recording
- Anonymity / confidentiality
- Can withdraw at any time
- If distressed can talk to me (or Mark)
- Research – no right or wrong answers
- I don't have a theory `I am seeking to confirm, rather I am hoping to generate one
- Hope to publish
- Will provide summary of requested
- Any questions?

General background information:

1. Which guideline were you involved with?
What was your role? (user / carer / psychologist / psychiatrist)
2. How long was the development process?
3. Has the guideline been published yet?
4. How were you recruited?

Semi-structured Interview Questions

1. Did you have any expectations about how your views would be received?
 - What? Why? Were these met? How? Examples? Power, Influence, Did GDG training influence this?

2. Did you have any expectations about different participants (service users /carers / psychologists / psychiatrists)?
 - What? Why? Previous experience? Were these met? How? Examples? Psychiatrists, Psychologists?, Users?, Carers?, Power?, Others' Influence? Relative values of evidence and experience?

3. Did 'scientific evidence' have a meaning to you before / during / after the guideline process?
 - What was its significance? Where did this come from? What was your experience of this like? Did it seem to change? Why? Relative values of evidence and experience?

4. . Did 'personal experience' have a meaning to you before / during / after the guideline process?
 - What was its significance? Where did this come from? What was your experience of this like? Did it seem to change? Why? Relative values of evidence and experience?

5. Did 'scientific evidence' seem to have a meaning to other participants (service users, carers, psychologists, psychiatrists) before / during / after the guideline development process?
 - What gave you this view? Examples? How did this impact on the guidelines / group? Did this seem to change? Relative values of evidence and experience?

6. Did 'personal experience' seem to have a meaning to other participants (service users, carers, psychologists, psychiatrists) before / during / after the guideline development process?
 - What gave you this view? Examples? How did this impact on the guidelines / group? Did this seem to change? Relative values of evidence and experience?

7. Was consensus generally reached on the topics discussed?
 - Why? How? Examples? What happened instead if no? Heated debates? Was this resolved? Did people exchange arguments / positions? Weight / airtime? How were people included? How were discussions directed? Were others p.o.v.'s understood / considered?

Appendix J

Final Interview Schedule

Semi-structured Interview – Draft 8

Introduction

- Hello and thank you for your time
- Introduce myself – trainee, service user, carer, GDG member
- Check documents (consent form, participant info sheet)
- I am investigating people's views on guideline development
- Perspectives and relationships of/between service users / carers / psychologists / psychiatrists – describe service user and carer experience / scientific evidence
- Length of interview – 1 hour
- Introduce taping
- Anonymity / confidentiality
- Can withdraw at any time
- If distressed can talk to me (or Mark)
- Research – no right or wrong answers
- Hope to publish
- Will provide summary if requested
- Any questions?

General background information:

1. Which guideline were you involved with?
What was your role? (user / carer / psychologist / psychiatrist)
2. How long was the development process?
3. Has the guideline been published yet?
4. How were you recruited?
5. Age / ethnicity / work and education background

Semi-structured Interview Questions

1. Was there anything you remember about the way you were invited to talk about your experience as a user? How did psychologists fit in here?
2. In your opinion, what can service users contribute to treatment guidelines? What is the role of psychologists in this?
3. How was research evidence introduced / elicited / used / what was valued? What did others seem to think? Why? How contrasted with personal experience?
4. How was personal experience used / what was valued? What did others seem to think? Why? How contrasted with evidence from research? How different if service users were not present?
5. How did service users and mental health professionals develop recommendations for the guidelines? How did you feel about the recommendations developed by the group?
6. How did you feel about the other mental health professionals on the group? Why? Was this expected?
7. Were there any mechanisms that prevented the guideline from progressing?

Appendix K

Summary of Categories for Consultation

Research Interview Findings

1. Interpersonal factors (relationships)

This section described the relationships that emerged between people, for example many interviewees spoke of alliances developing between people from similar backgrounds (e.g. psychiatrists with psychiatrists). Some service users were pleased they had been able to develop collaborative relationships with professionals.

Social skills were very important, and helped some service users feel welcomed and included, though some described how the communication between people outside the formal meeting could alienate them (for example asking questions demonstrating assumptions in the break).

Service users had sometimes worried beforehand about the extent they would be listened to. Some predicted there would be an element of competing for power among group members, which was sometimes found. Most people agreed that proceedings tended to be led by psychiatrists. As such though 'everybody is equal, some are more equal than others'.

Some people referred to the idea communicated (sometimes subtly) that things had to be done the way NICE expected (e.g. focusing on RCT evidence).

2. Types of evidence: Presenting research or experience

This section consists of reflections about the different types of evidence used (research vs experience) and the criteria which make for a successful user representative or mental health professional in a guideline development group.

Group members acted as both witnesses (describing their evidence e.g. research or the user's point of view) and jurors (deciding on recommendations).

Psychologists were viewed as either helpful allies, too similar to other group members to distinguish, following their own research agenda or burdened by too many demands

Some participants referred to not having much exposure to the tough demands of research evidence before starting the group and were concerned that it might drown out service users' voices. However some people said research evidence was robust, and national guidelines needed to be evidence based. Research evidence tended to feel most relevant to medication-related topics.

On the other hand, research evidence was sometimes so narrowly focused that it missed the point and it often didn't or couldn't exist for interventions that service users found helpful.

Most people had drawn on personal experience (and that of others they had had contact with) rather than explicitly using personal examples. Lots of people felt user perspectives couldn't be fed into the process fully – through evidence not existing and service users often lacking the same familiarity with the methods for interpreting research as professionals.

However almost everybody agreed that user perspectives were unique and vital to the process, Service users were perhaps acting as a kind of 'failsafe'. They could prevent inappropriate language and assumptions being accepted, to keep the whole person in mind and to provide credibility to the guidelines by witnessing their development. Users having a contribution to the scope (questions the guideline addressed) and defining important outcomes (e.g. deciding whether symptom reduction vs. change in behaviour should be the goal for treatment) was also seen by some as a valued role. Many people commented that professionals drew on their own experience of professional practice.

Some people were invited in to conversations frequently whereas others had to be more assertive. To be a successful service user representative, an 'x' factor was required, experience of involvement initiatives, presentations, research / statistical / academic qualifications and assertiveness were commonly described as useful attributes.

Successful professionals were imagined as being flexible, open to qualitative data, experienced in user involvement and having specialist experience.

3. Rigorous process (the formality and traditions of the process of developing guidelines)

This section described the traditions and the formality and arbitrary nature of many of the processes involved in developing guidelines. These could contribute to user representatives feeling somewhat daunted by the prospect of being involved.

'Testimonials' (service users' accounts of their experiences) were included in some guidelines but not others, and they were missed when not present. They helped bring in the breadth of the disorders guidelines were addressing.

Some people described being recruited by reputation, having become known for involvement initiatives they had participated in. This was mentioned as a cause for concern by one representative who felt a formal selection process might be better.

Training was offered in statistical methods but it tended not to be exhaustive, leaving areas of uncertainty.

Sifting the data was reported to be a dry process that user voices couldn't be easily fed in to. People tended to suggest a need for greater attention being paid to commissioning and finding relevant qualitative research.

People agreed the guideline had to be robust as it was important. but time pressure often meant decisions were forced.

People were often in awe of the other members given their reputation or service users' prior experience (e.g. of psychiatrists) though others were quite comfortable with the format, particularly when they already knew some of the other group members.

4. Deliberating (inclusion in reaching a verdict)

This category describes people's perceptions of the ways evidence was weighed up and conclusions (or the verdicts) were drawn. Positives and negatives were described. In several accounts recommendations were described as sometimes being overturned by higher structures (e.g. NICE) due to financial or practical constraints. Other comments suggested that the scope being decided beforehand and quite rigid often presented a problem as there were areas people couldn't bring in.

People described their influence in the final product as often being about good practice points, the tone or context. Due to the size of the document single points tended to get swallowed up. Some people were pleased they had been able to teach something to the professionals. Others felt they hadn't been able to fulfil the role they had been invited to take because of the dominance of research evidence.

Jargon presented an issue for some in that technical terms seemed to be a 'foreign language', though some felt more able to learn this than others.

It was difficult to integrate research evidence and experience. Some people had confidence in professionals in their group to make decisions about areas they themselves weren't familiar with though others were frustrated they had no choice but to do this. Some people felt the two types of data (research evidence and user experience) agreed on some subjects, others felt they complemented each other, for example using professional judgement based on experience when evidence was irrelevant. Because user experience is often broad and the research evidence narrow, the traditional argument that the individual experience is too individual and RCT evidence more generalisable may be the wrong way round!

Some people reported that information was not always shared, though this was not a problem for those who found it rather dry! Some people reported feeling fully included when information sharing was 2-way.

There was some discord described within groups though it was usually thought to have been handled well (typically by the chair) and was often conducted with polite professionalism though some people referred to members criticising other professionals' research.

Though people within groups tended to have the same general goals (to make people better, to have the best treatment guidelines) the details of these aims were not necessarily shared. One person's idea of a good guideline may not match another's. Compromises had to be made but it was unclear for many what the formal decision-making process was.

Being 'held in mind' (points individuals made being retained across several meetings) helped people feel included.

Service users generally they were 'experts by experience'. This expertise could be created by being exposed to events and situations where the experience is processed so context, different perspectives and confidence develop. Some people felt more appreciated in this role than others.






Many people used the term 'around the table' suggesting perhaps the democratic round table used by King Arthur. People could be helped to feel equal (sometimes despite the above) by 'professionals' also having difficulty understanding the statistics, by people using empathy and by the chair asserting their influence and the user and carer concerns slot being taken seriously.




Appendix L

Example of Participant Feedback on Consultation Document

Microsoft Outlook Web Access

06/14/2008 11:37 PM

 Send |  |  | Importance **Normal** | Options **None** |  Close |  Help

 To:
 Cc:
 Bcc:
Subject: **FW: NICE guideline research consultation**

Attachments:

Hi Emma,
This all looks very sensible - it certainly fairly reflects a lot of my experience.
Thanks,

Appendix M

Example Interview Transcript

N.b. 'Christine' is a pseudonym. To protect confidentiality, some information (in brackets) has been omitted or changed. Christine had asked for a copy of the questions in advance of the interview as she was anxious.

Interview with 'Christine'

C = Christine

R = Researcher

R: Yeah, ok well kind of moving on to the kind of the main body of questions, before you started being involved in the guideline, did you have any expectations about your role? In the process?

C: Erm, well I wasn't quite sure, uh, I wasn't quite sure how I was going to fit in. I was a little bit daunted, I felt daunted even though I had worked with health professionals. Um, I wasn't quite sure what my role would be, and I had read a bit about it and it said some service users contribute to the writing, and things like that so I was quite happy about that, and obviously this is going to be just typical to me, because ...[omitted to preserve confidentiality]...I was concerned about how it was going to be because it is a big group. You see I am very experienced with committees but with a group it is quite difficult. Um but um, I didn't really have any firm expectations as such I don't think. Erm I was a bit concerned I have to say about psychiatrists

R: Er, Ok

C: I haven't got much faith in psychiatrists and I'll admit that.

R: Yeah, and where did that come from?

C: Erm my experience...in hospital and before I went into hospital, I didn't have any confidence in psychiatrists at all

R: Yeah, and you said you felt generally quite daunted

C: Yes yes I did because I thought 'here are all these very professional people, the experts, and there's little old me that's had this experience and it was a long time

ago...[louder] Actually if I can say, that was unfounded. Because the psychiatrists that were on the group were all very interested in the area – of course they would be or they wouldn't be here. They were all passionate about the area of ...[speciality]...and I thought they were all very understanding. Wonderful...[laughs] so it changed my ideas! There was just one who was a little bit aloof I found, but I was expecting a real feeling of power from these people and I suppose there was little, posturing you know at the meeting

R: How did that play itself out, posturing, how did you recognise that was happening?

C: Oh because people would start to use lengthy terms...I mean I know you've got your question later...and try to use some sort of research terminology which some of the other health professionals didn't understand. So the chair, we had a very good chair who said 'explain that' or would actually say 'I don't understand what you mean by that' when I knew jolly well that they did know' and it put them in their place. And that was quite good actually I think.

R: Oh that's good, that someone was actually able to make it accessible to everybody

C: Yes I think so I think so, though it was very difficult to interject I have to say that but I think it's quite...I think the other service user found that as well, because there was a lot of rapid fire discussion um and I think mainly because of [omitted to preserve confidentiality] it takes me a long time to interpret what was being said, I could never get in quickly enough! [laughs]...so you had to kind of put your hand up and you had to have confidence to do that don't you, to say there's something I want to say. And the chair was very good, he was watching out for us, to make sure, to let us have space to think.

R: So he would make space

C: Well there was a set space anyway um, during – I don't know whether you had that with yours? Did you?

R: Yes, an agenda item

C: Yes yes. But he would, if he could see we were going to say something and he wasn't too involved in what everybody else was saying he would say 'oh yes Christine you have got something to say there?' so that was quite good.

R: It sounds like he particularly made that a bit easier for you. But you said you had to have some confidence sometimes to put your hand up and try and interject, and I get a sense that it was quite hard for you to get a word in edgeways

C: It was, it was, and sometimes by the time he had noticed we wanted to say something [laughs] they had gone onto something else!

R: Yeah

C: Um, but I think you are able to overcome that by the fact that you are able to see everything that's written, anyway and you can read the minutes, I depend so much on the minutes er, and you can add to them the next time you know and I said 'ooh was that really said?' because you could say 'I didn't say that' or whatever. Or 'I don't remember that being said' and the fact that you had actual input to the guideline itself, you could see it and put comments on in different colours and that was and that was helpful

R: Just so I can understand you...you were able to write comments on the guideline as it was developing and is that what you were...

C: [Nods]

R: Oh, ok.

C: You had that process as well did you?

R: No we didn't, but it all sounds quite positive and

C: Yes it was...we had a special site ...because ours was probably later than yours, I don't know how long ago your was?

R: I think mine was published in 2002 or something

C: Oh right. And it would, you could log into it and adjust it and it would using oh...what's it called...tracking. It came up in a little colour according to who had made comments. And er that was quite good, because some of the terminology that was used erm, I didn't like, I took offence to. Just, just about words people use. Erm, for example 'How are we going to *manage* the [client] erm I object to being managed...if someone says they are going to *manage* the [client] I mean I think quite possibly they capable of *managing* themselves. You can care for them, lets use the word *care* as an example of some of the things that were said. And I think that they were sensitive to that,

R: So it sound like they did take your comments on board, and

C: And also the other service user as well, and also I didn't like being called a 'patient'

R: Mm mmm

C: And I didn't think you should have the word patient in there because they are [people], you are talking about [people]. And I much preferred the 'service user' to 'patient' erm, yes I got a bit fussy about words.

R: And did you get a sense that your..on the ..th your stance on the ...the language was taken seriously, and did it change things?

C: Well I feel that they did try I think but there were other areas that we will come to...

R: Yes I am sure. Ok and did you have any expectations about how your views would be received?

C: Well as I said because my experience was so out of date erm I thought that, no notice would be taken of what I said I thought they would want someone with more recent experience and I was quite horrified actually to find out that nothing had changed! [laughs]..you know all the bad...bad experiences I had had. With regard to psychiatric treatment and my treatment in a general hospital then going to a psychiatric hospital it hadn't change so that...that expectation wasn't fulfilled that they wouldn't take any notice of me, that was my main concern.

R: In what ways did they take notice of you, how did they prove your expectations wrong?

C: Erm, well by making some adjustments to the guideline actually...because that was a big issue, something came out, after we had done all the talking around the table and we had all made our comments on the guideline a draft came out and it looked nothing like what was actually said and so er people got very angry actually and um, one of the psychiatrists said, well in fact a group of psychiatrists said they would actually withdraw and they wouldn't want their name attached to the guideline if it was going to go through in that form. It was almost as if it was politically led ... you know we must recommend too much because it will cost a lot of money.

R: Oh yeah

C: Do you see what I mean? and I felt that perhaps some people were working to a certain agenda and things that had been decided before we actually...because what we wanted was going to be too expensive to recommend basically, or it would appear too expensive so the er, the psychiatrists got together and said we are going to withdraw and it came round on email to all of us and I put in my comments and said 'yes as a service user I agree with you, I will join you wholeheartedly...we have had the experience and

this is what [clients] must have' and notice was taken...[laughs] so we stood together on that and notice was taken, and I felt that we really had a good input there, both of the service users

R: It sounds very political

C: And it still wasn't perfect, I have to say that.

R: And how would you say you saw your responsibility as a service user on the guidelines?

C: Well it is a tricky one, yes it is a big responsibility when you are speaking on behalf of a lot of people who have had....well I wouldn't say a similar experience but have had *that* experience. Um but it is interesting because the other service user on the group um had had a very different experience to me erm and had a very different background to me erm, a very different background completely. Um also, she also had [an experience] and was from a very different social background because I am from ...[background]...[laughs]. Erm but we thought among the same lines, we had the same ideas which was good, erm, so but I did feel a responsibility to others, so you know and also to keep quiet about things as well. You know you had to be careful not to speak, as I was working with health professionals I had to not say anything about what was happening on the group and things like that. I did say that I was working in the guidelines but I couldn't release any information

R: Yes it is difficult

C: And obviously I had to tell them at [workplace] that I was doing this 'cos, 'cos, in fact all my money that the fee that they give the service user went to the [workplace] so that I could take the time out of work to go to the meetings

R: Oh that's good.

C: Yes and that's how I did it.

R: Ok, and was there anything that you remember about the way that you were ask... invited to talk about your experiences as a service user?

C: Erm, well as I said we were given time in each session on the agenda to actually speak about it, but as I had had 3 [experiences of illness] there was quite a lot to say! but what I found was really good was when we put forward, when we had to write about our experiences,...[omitted to preserve confidentiality]... so that was fine. But I had not actually [omitted to preserve confidentiality] said anything about my experiences because I had sort of put them in my pocket and forgotten about them – it happened a long time ago and nothing as happened since so erm, ..er it was good to be able to write about it actually. It took me a long time and I found that quite, quite upsetting to write, it was all coming out and I had this great...I thought 'this is going to turn into a book if I am not careful!' they only wanted 1500 words and you can't write an experience in 1500 words! It ended up as 3000...I think that was the best way actually. I mean I gave little bits of information, we were asked to introduce ourselves and say a little bit but we didn't talk fully about our experience in the group because there wasn't time...so I was good to actually have that experience to write about it. And then I circulated it to everybody by email and everybody had a chance to read about it and then they...I don't know whether they did on your guideline but they collected testimonies from other service users...now that was so good, they got testimonies from other service users and from professionals and they were used within the guideline...in the full guideline extracts were used to illustrate the points in an interactive way which is what we, what the service users wanted all the way.

R: And at what stage did you circulate the summary of your experience to other people on the guideline?

C: Towards the end actually. And because my job, I was so busy in my job and I kept trying to start writing this thing but I was also trying to write course guidelines and things ..and I kept wanting not to bother with it. I don't know, I did find it, it was quite cathartic in one way and I found it quite upsetting and I found it as I said very difficult to keep down the words so it was, it was towards the end actually when they were collecting the testimonies I suppose when we were about 18 months into it. So I think they didn't really have a full picture of my experience and I think it would have been good if I could have got that done right at the...[omitted to preserve confidentiality]...but um they didn't really know very much about my experience I don't think. I don't know if that would have...hmm

R: I was just wondering if there were any times you remembered any times where people had actually sought your experience on something to help make a decision on something or a recommendation or something?

C: Erm only when we sort of interjected. For example um...we were talking about ...[services]...and er because I had to go into a general ...[service]... the first time and there were all sorts of things going on there. And I was only there short term for a week erm and then they got me out and I got home again and the second time I was in a general psychiatric unit on a ...[service]... which was a bit scary [laughs]... erm and very confusing. So I feel, I felt there has to be a special place for, ...[patients]... should never ever be put in that situation erm, so they did try to get my experience on that actually. And the last time I didn't need to go into hospital they managed me at....cared for me at home ...see I have used the word 'managed' there it is a habit, so I was cared for at home and that was ok. With a whole load of all sorts of people – my husband and my Auntie [laughs] you know until I had come back' again. But erm I didn't really feel though that there was much probing, people didn't want to do that, they wanted to volunteer the information more than specifically ask you

R: And what do you think was their motivation for not wanting to ask you was?

C: Probably erm they were frightened that we may...become upset, because I mean I explained it was something as I said that I had put behind me, and experience that I had put in my pocket and I took it out and unwrapped it to have a look at it again for the guideline. [Omitted to preserve confidentiality] .

R: And is there anything you can remember about the way psychologists asked about your experience or had any particular role?

C: Um, I can't really, I think er psychologists, I was trying to think about this and, er psychologists I um I think they had very, we had two psychologists on our group and they were very open and encouraging I thought, very attentive when you did manage to speak erm, and um I found them very encourag...they need to listen very carefully. Um I have views about psychologists and interpretation of research but maybe [laughs]

R: Maybe a later question will cover that?

C: Yes and it is very difficult to say how I viewed their roles because everybody was much of a muchness on the group because the way the chair acted, he gave equal weight to everybody and they they were fine the psychologists

R: And would you say that you could distinguish between professions? In the group because you said people were much of a muchness?

C: Well I think obviously they all introduced themselves at the start...no actually really, um just see. Well actually they were bringing their experience they'd had, their professional experience so in that way they all had something to give and were coming at it from a different angle, a different perspective was coming in, so you had to, you needed, it was so important. Erm, ...I I can't say I mean something, some people, thinking of the psychiatrists they were very experienced in dealing with, in working with and caring for [people with mental health problems] and they were very obviously keenly interested about it.

R: Mmm that's interesting thank you. It is interesting the idea of evidence being looked at by different professions in slightly different ways

C: Yes those different perspectives, that is so important.

R: Well my next question was kind of ...um...so in your opinion what can service users contribute to guidelines?

C: Well it is um, their experience is so important, um obviously everything that they can bring and their opinions are very very important and I think although, I came to the end of the guidelines thinking 'well there are all the experts here, but who are the experts really? The service users have to be seen as experts because they have the experience they have gone through this thing, they know how professionals treat them, they know you know their own bodies, they know their own minds and um and they are the experts and they have to be listened to, and that is so important.

R: And you said that them bringing their experience was very important but in what ways would bringing their experience have altered the treatment guideline?

C: [Omitted to preserve confidentiality]

R: So kind of identifying priorities,

C: Yes yes, issues of relationships and power relationships and being aware, I think we were, we were [similar] but you know stress, there are some people out there who may not be able to say 'I don't want that' or 'I don't understand that' – you've got to explain it to me' I think that kind of experience

R: So having your experience, I am kind of summarising really, you're able to let professionals know for service users who are less able to assert themselves what their

priorities, what other service users have identified as priorities for themselves. Yes that's really interesting, service users kind of identifying the priorities, even the scope of the guidelines

C: I can't say that everything was actually taken on board but we will go on to that

R: Well the next question, how do you feel research evidence was kind of introduced to the process of making decisions on the guideline development group?

C: Er, ok this is my big thing. Well they er circulated some articles to read er and various things, and of course I couldn't stop myself from doing my own reading outside that um and finding my own research papers, and em having sort of um, it was all introduced as being all very statistical erm and erm that is where I was at one time in my own research, I thought you had to measure everything you know it had to be, you had to do so many counts and you have to put it through the statistical mincer and out it comes with results and 'yes oh yes it's significant' and all that and I, I moved away fro that and so I found articles that were qualitative, based on qualitative data erm and I took them along and I didn't hear any more about them [laughs] and we both kept saying 'you've got to have the voices here' and in fact they did use extracts in the end. But time and time again 'we have to have randomised controlled trials' over and over again. And I really don't think that works when you are talking about people's emotions and mental health you can't have...sort of put people's feelings down in a set of numbers and some of the studies, which were, were using this thing called the [name of scale] scale and you are asked these questions and you tick the boxes and you are given a score and if your score is ...[describes scale]...these thoughts and feeling can't be expressed in numbers and we kept saying 'oh we don't like this' and [name of scale] was being used across the service, the services, really just for detecting it and it was a question of [clients] going in and ticking the boxes and they admitted, in the testimonials they admitted to making it up! So erm they did take heed of that a little bit and it turns out I the end that there is very little research that could be used but it all depended on these wretched randomised controlled trials!

R: And at what point had you moved away from that idea, that research methods...

C: When I was doing my [studying]

R: So before...before the guidelines

C: Oh yes yes yes because it was when I was actually [studying] erm, having used focus groups and these working class women and er I thought 'I can't' because I was straddling the border, part of me wanted to do counts and I used a computer package and counted how many times they said this and that sort of thing and drew lots of bar graphs and that sort of thing. [describes studies] So that was when I felt, you know that you needed the voice. And the sort of research you are doing now to me, its far more real in a particular area. I think randomised controlled trials are fine for something like I don't know; lets say somebody's got a leg ulcer and they are trying out a different form of dressing, um, you know if that works then it works – you know what I mean. Um and I just feel that with my own feeling that with people's thoughts and feelings, they may have some part to play but not enough weight is given to qualitative evidence.

R: And it is interesting you talking about RCTs and it might be ok if there is a simple outcome such as a leg ulcer, if the bandage works it is easy to tell and if it doesn't, so in terms of that differing from people's thoughts and feelings you have talked about not being able to reduce that to numbers – ifs that because there is a sort of continuum of...where it is harder to point out hen something has worked and when it hasn't?

C: Yes! Yeah yeah and because I think it abstracts the person, and the person becomes just a set of symptoms and a set of numbers and you can't do that. I think and it forces people to think of the professional to think of the person as a set of symptoms rather than this whole person.

R: Mmm

C: And this whole person goes from here and has all sorts of things going on out there um is not the same, may not be the same person that they see.

R: And you said as well in the testimonies that people had said they had...had kind of lied...a little bit or made up their responses to the scales...

C: Yes because they were frightened...perhaps that they'd be diagnosed and...[experience a difficult event]... something like that erm, so um yes I I think they give a very very false impression

R: And it sounds like there is a bit of a difference, that you are implying between being diagnosed by a scale and being diagnosed by a clinical interview.

C: Mmm mmm mmm yes yes very very different and some of these trials they haven't had a proper clinical interview

R: yeah, ok. And how was the research evidence used, what was valued by the people in the group generally.

C: Well as I say the research evidence was all on the quantitative side and that's what was valued, erm, we had a very good person there who was doing all the analysis, I think she was a statistician, and she came along and had several of those and showed us a book and people just said emm, yeah and nodded [laughs] and we would think hmm, we believe you [laughs] omitted to preserve confidentiality]

R: Although you were jesting a bit when you said people would present the evidence and how you'd interpret it and you would just say 'we believe you' as a kind of I wondered if that was about letting other people make the decision or it not feeling relevant

C: Yes yes yes in what way do you mean?

R: I have got myself into a bit of a philosophical corner! I mean when people just nodded and agreed with the research evidence was that because they were trusting other people to make the decision without wanting to engage in debating it?

C: I think so, yes yes the majority of people couldn't interpret it, they really couldn't! erm so you know the psychiatrist, everybody was sort of looking at it sort of thing, which was a bit worrying, that they weren't able to interpret it. Because there were some techniques that I wasn't familiar with that were being used, I mean beyond the basic levels and things like that. And she did her best to explain everything and it was all displayed to us but em, hmm numbers er, it wasn't people it was numbers.

R: And it was interesting you saying that most people couldn't interpret it, so I wondered who was left with kind of making the interpretative decisions, was it the kind of methodologists?

C: Yes yes yes

R: Was there anything else you wanted to say about research evidence? You said that was a big area you wanted to cover?

C: I think that was my big thing, like the fact that erm you know that the qualitative, any qualitative evidence was put on one side

R: Even though you had specifically brought it

C: I brought articles that were qualitative, based on qualitative data but they, and I had them photocopied and circulated but they were never drawn on.

R: Yes and it sounds like

C: And they were in very good journals, international journals. But it was a no no, all we kept hearing was the RCTs!

R: And I noticed you saying that even after you circulated the papers nobody actually referred to them ever again as if they had sort of gone underground or something.

C: Mmm mmm

R: And as a contrast, how was personal experience kind of introduced or used on the guidelines?

C: As I said there were testimonials collected from other service users and my own testimonial um, a part of that was used and included in the guideline, well included in the full guideline the sectional thing. And that was used very much to tie it up, very much like a qualitative article is, that actually, that was good the fact that evidence was used to illustrate major points that came out of the guideline. And that was part of the evolution of the guideline, as we were going through, both us service users saying 'we want more qualitative stuff' and it had been used in other guidelines as well.

R: And how did other people seem to view and value the idea of service users sort of having an input and talking about their individual experiences

C: How did people value it, which other people?

R: Other people on the guidelines, the people who weren't service users, how did they seem to feel about service users having a role and contributing from individual experiences?

C: They they were fine oh yes. I felt particularly the psychologists and the psychiatrists valued it very much erm, ... there were, there was one psychiatrist I think that thought that we were er, being a little bit too confident in what we were saying!

R: That's interesting!

C: I got the impression that er I could see her facial expressions as we were saying things and she, she was ok, oh I shouldn't say she [laughs] but I just felt that she er

R: In what way did you link that to her views about your confidence? What led to that?

C I don't, I don't know really...I think because I had very strong views about, um about ...[treatment]...and she didn't like that idea – that was an issue for example.

R: And it was, she was a psychiatrist you were saying

C: She was a psychiatrist and obviously I had views about [client group] and we both had views about that into a psychiatric hospital...and she just slightly, a very slight issue there. Um and another health professional got a bit uptight one day and said, thought I was in denial [laughs] – I found that upsetting, I don't know, if I was in denial I wouldn't have been there! [laughs]

R: That's true!

C: I think she had a bad day

R: It was interesting you talking about the slightly, subtle discord in the group and you were saying the psychiatrist was quite, I know you said it was only a slight, subtle

C: It was only very slight

R: Kind of obviously her viewing the medication and hospitalisation as a priority and you seeing [omitted to preserve confidentiality]

C: Absolutely because she only sees them in a different environment, not in the home environment erm, that was an issue. But there we are.

R: That's really interesting actually! Anyway um, was there anything else about personal experience being used that you wanted to talk about?

C: Erm I can't think now that there is..erm no I don't think so so

R: And did the language people used indicate anything about their position in the group or their power or their status?

C: Erm I think to start off with, um there was as I said a bit of posturing and a bit of power positioning, and I think um that can be a lot of problems because as a service user there are always these power differentials between the professionals and the service user .. that we had to overcome I think... um, because they like to think that they know best. But I think once we had become more used to each other everything relaxed. And um, yes I think so. I mean my problem was my hearing anyway and I couldn't join in with the conversation when everybody is having lunch because [omitted to preserve confidentiality]. And I er I think I said to you earlier on that there was the terminology but the chair was so, so good at breaking that down but it was the sort of in the early stages the power differential that we were service users and they wanted to call us patients and they were the professionals and it had to be, had to be eliminated so we were all equals

R: Absolutely and what was the role of the psychologist? In kind of that language gap between...

C: I don't think the psychologists were too bad, um, one psychiatrist mainly in the beginning, the psychologists weren't too bad. I find it very difficult to differentiate how they behaved. Trying to think back now because it is over a year ago. I found everybody

fine really I can't really say that anyone tried to be a powerful person at all, the psychologists they didn't really exhibit that. Any sort of posturing anything like that.

R: and did they have anything to say on the sort of patient versus service user terminology debate? If that actually happened actually, I am just sort of assuming that there was some discussion.

C: No I don't think there was no, In fact one of the psychologists was really sort of very respectful of us particularly and was very good, and she said 'oh we'd like you to come and have a look at this, we'd like your views on this' she was very very good, we want your views on this because you have got this sort of background it was good

R: And it sounds like a pity that at lunch you weren't able to be part of the gang as it were,

C: Yes it was it really was. Because I was a fairly quiet member of the group because there was rapid fire discussion going on, I felt my real contribution was being able to read things and make comments on the guideline, not that actually what I said was, well it was taken notice of, changing the words which we talked about previously. But yes the lunch I would have liked to have stood around and talk with everybody, although I used to go and take my lunch back into the other, back into the room and one or two others did as well and they would come and chat. And there was one psychiatrist there who was so lovely she was so gorgeous and she just didn't seem to have that power and she never put herself in that power position at all. And I thought 'if I'd been ill I'd have loved to have seen her she was super!' really was good, so nice and so quiet person, not like the others!

R: And you were saying obviously you had quite a lot of input on the written document, making comments in it and I wondered what the feedback was on your comments in the feedback on that process?

C: Well nothing very much, nobody really said very much we just all sort of made our comments and then it went on and the editing took place and we just as I said earlier quite upset that sometimes notice wasn't being taken of what we said and we felt things were being channelled along a particular way

R: Almost as if there is a predetermined idea?

C: Yeah yes um but um I did feel that I did succeed in some areas as regards to language. Notice was taken

R: And what skills do you feel a service user needs for a successful guideline development process- what do you think important qualities could be?

C: Well that's very difficult, and I have thought about it [laughs]- well the experience is important, they need to be able to look back on that experience and I cant say objectively because you can never be objective about your own experience, and be able to relate that experience to everybody else, and you have to have empathy obviously to understand other people's thinking. I mean also we have to be able to understand, I know that I said I was a bit mistrusting of psychiatrists, but you have to sort of put yourself in their shoes as well to understand their working to a sort of certain extent, um other skills, I think they have to be able to interpret research, to be prepared to read and interpret try to interpret research evidence and to have time to read it and read around the area as much as you can and um, oh it would be good if I had some good ears! [laughs] then I could hear properly what is going on! And you have to be able to speak into a large group, and that is to go into a large group if you haven't been used to committees is very daunting!

R: I can imagine actually, and as well as the experience of using services it sounds like there is other experience you have had which has helped you, like your experience with committees and with speaking to big groups of people.

C: Mmmm

R: And another difficult question! What do you feel the ideal qualities of a psychologist might be to succeed in a guideline development process?

C: A good listener, got to be a good listener, and be a person who is very open, not rigid in their thinking – somebody who, obviously I am very biased, somebody who gives weight to qualitative evidence!, erm and doesn't get all tied up in the stats, erm..yes that's it, someone who is not a rigid thinking along those statistical lines. And is a good listener. Yes and empathetic

R: And now the final question or the follow up one, how do you feel about the guideline or the product now it is finished? Your reflections on having been involved in developing it?

C: [Omitted to preserve confidentiality]

R: It sounds like you did a lot of representing others

C Yes yes I didn't want to just talk about my experiences so I had to draw out what other people said and do that

R: And I just wanted to squeeze in just one really last question, um which is about in the final, obviously there are different versions of the guideline as you said before, the patients' version, the public version; where do you most see your influence in the final product? Which are the bits you feel you have contributed to most in the different versions?

C: Um, well obviously the service user patient carer guideline, we put quite a bit in that um, also we contributed to the full guideline, we came in as service users again to work with the person editing it and finishing it off to discuss al of the testimonials and actually help with the analysis, pulling out the pieces which we thought should go into the

guideline. So we had a big input in that in illustrating issues which were raised in the guideline so I think we had a fair amount of input all the way through.

R: And was there anything else that you were thinking of saying that we haven't covered?

C: I can't think, no. If anything comes...

R:...Absolutely do email me or whatever

'Research Log Checklist'

Research Log Checklist

Formulating and testing hypotheses and research questions	I have generated and tested one set of hypotheses for my SRRP and done the same for research question in my MRP.
Carrying out a structured literature search using information technology and literature search tools	I have used Athens databases to search the literature on three research topics.
Critically reviewing relevant literature and evaluating research methods	I have critiqued literature pertaining to both the content and process of my research projects (SRRP, MRP and Qualitative project).
Formulating specific research questions	I have specified research questions for qualitative research project, MRP and SRRP based on literature searches.
Writing brief research proposals	I wrote brief proposals for my SRRP and MRP.
Writing detailed research proposals/ protocols	I wrote a detailed proposal and protocol for my MRP.
Considering issues related to ethical practice in research, including issues of diversity, and structuring plans accordingly	I considered the power relationships and diversities generated by my interaction with interviewees in my MRP.
Obtaining approval from a research ethics committee	I gained approval from the school of human sciences to proceed with my MRP.
Obtaining appropriate supervision for research	I gained supervision from a course team member with an interest and experience in my topic of choice for my MRP.
Obtaining appropriate collaboration for research	I identified and gained collaboration from a field supervisor for my MRP.
Collecting data from research participants	I collected data from 10 MRP participants.
Choosing appropriate design for research questions	I selected a design suitable for the research question in my SRRP and MRP.
Writing patient information and consent forms	I wrote a patient information leaflet and a consent form for my MRP.
Devising and administering questionnaires	I designed a semi-structured interview protocol.
Negotiating access to study participants in applied NHS settings	I negotiated access to NHS service users, carers and professionals working on NICE guidelines for my MRP.
Setting up a data file	I designed and inputted data to a file for my SRRP.
Conducting statistical data analysis using SPSS	I used SPSS to generate statistics for my SRRP.
Choosing appropriate statistical analyses	I identified and used statistical analyses suitable for my SRRP data.

Research Log Checklist Cont'd

Preparing quantitative data for analysis	I inspected and inputted data relevant to my SRRP project analysis.
Choosing appropriate quantitative data analysis	I selected a quantitative approach suitable for my SRRP data .
Summarising results in figures and tables	I have presented research results in figures and tables in both my MRP and SRRP.
Conducting semi-structured interviews	I have conducted 10 semi-structured interviews.
Transcribing and analysing interview data using qualitative methods	I transcribed and analysed 10 semi-structured interviews for my MRP.
Choosing appropriate qualitative analyses	I selected a qualitative methodology suitable for the topic of my MRP research.
Interpreting results from quantitative and qualitative data analyses	I have interpreted and discussed quantitative data in my SRRP and qualitative data in my qualitative project and MRP.
Presenting research findings in a variety of contexts	I have presented my SRRP research findings in an academic meeting and to professionals involved in the setting for my MRP.
Producing a written report on a research project	I have fully written up my research for my SRRP, MRP and qualitative research projects.
Defending own research decisions and analyses	I defended my MRP research in a viva voce exam.
Submitting research reports for publication in peer-reviewed journals or edited book	I have written up my MRP findings in a more concise paper and submitted it for publication.
Applying research findings to clinical practice	I have utilised lessons learned from my MRP and SRRP in my interactions with clients and colleagues on placement.

'Media Representations of Mental Illness'

Qualitative Research Project Abstract

July 2006

Year 2

Qualitative Research Abstract

Rationale:

Representations of mental illness, specifically schizophrenia and psychotic illness in the print media did not match the understanding of the authors. Research such as the SHIFT Report (2006) indicate that this is widespread. We hoped to generate a conceptualisation of the power differentials between people with mental illness, the general public and the media.

Methodology:

We opted to use critical discursive psychology, combining discursive psychology with Foucauldian discourse analysis to facilitate an understanding of how texts depict issues of power using language (Coyle, 2006).

Sources:

Stories from 6 newspapers on one case during a specific time period were selected.

Analysis:

We each analysed a portion of the articles by identifying common themes and discussed our findings with the rest of the group.

Results:

Our analysis yielded five categories of discursive patterns: 'Mad or bad', 'blame', 'medication', 'outgrouping' and humanising / dehumanising'. We focused our discussion on this last theme based on the culture of our work as this seemed particularly relevant to the issue of power.

Discussion:

Media reporting was found to support hypothesised prejudices, using sensationalist language and drawing on categorisations such as 'good versus bad' so removing the need for readers to generate their own views. Language seemed geared to strengthening the reader's emotional reaction, implying the inevitability and enjoyment of violence in psychosis. The positioning of these themes visually and conceptually led the reader to dismiss the individual's identity beyond his behaviour. This occurred at a time of public concern surrounding mental illness.