

# **Types of Communication about Delusions among People with Psychosis**

(A multi-centre cross sectional interview and record study)

*A Quantitative and Qualitative Research*

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## Abstract

**Background:** Delusions are common in psychosis, defined as fixed, false beliefs. Some studies, however, have found that they may be less fixed than previously thought, possibly changing in response to talking about them. Relatives of people with psychosis or clinical staff often ask how to respond to them when they talk about their delusions, but no available advice appears to be evidence based.

**Aims:** To review evidence on everyday communication about delusions and find out how people with delusions talk about them with others, taking three perspectives (patients, their nominated relatives and clinicians) and to construct a model for communication in relation to the delusion according to each party independently.

**Methods:** 36 patients were engaged in semi-structured interviews about their mental state generally (Comprehensive Psychopathological Rating Scale) and their delusion (Maudsley Assessment of Delusions Schedule). Each patient was asked to nominate a relative *and* a professional to whom s/he spoke about the delusion. Relatives and staff were interviewed by different researchers.

**Results:** Most patients reported speaking to others about their delusion and nominated an informant. Most felt emotionally disturbed by their delusions, but, against prediction, this did not affect nomination; nor did their delusion content. There was good agreement between the three parties on occurrence of such communication. Some patients had self-harmed; only some relatives or staff concurred with them on attributing this to the delusion. A testable hypothesis was generated that the intrusiveness of delusions resulted in personal change for the patient and sense of changed relationship and detachment for the others.

**Conclusions:** No previous study has investigated communication about delusions between three parties. It was striking that so few relatives were engaged. If patients, their families and clinicians could improve mutual understanding of delusions, the safety of the patient and others as well as treatment might be improved.

## **Dedication**

I dedicate this work to my beloved wife Dr Mariam Matar whose unconditional encouragement and support made it possible for me to complete this work.

I wish to express my heartfelt love to my daughter Sara for coping with the undue paternal deprivation during these years.

Their sacrifices, which were realised by our loss of precious time together, were for me the most painful and humbling of all.

To my family, I love you all.

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## Table of Contents

<b>Abstract .....</b>	<b>i</b>
<b>Declaration.....</b>	<b>ii</b>
<b>Dedication.....</b>	<b>iii</b>
<b>Acknowledgments.....</b>	<b>iv</b>
<b>Table of Contents.....</b>	<b>v</b>
<b>Publications, Abstracts and Presentations.....</b>	<b>vi</b>
<b>Abbreviations.....</b>	<b>vii</b>
<b>List of figures.....</b>	<b>viii</b>
<b>List of tables.....</b>	<b>ix</b>
<b>Chapters.....</b>	<b>x</b>
<b>References.....</b>	<b>xiv</b>
<b>Appendices.....</b>	<b>xiv</b>

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## Abbreviations

The following table describes the abbreviations and acronyms used throughout the thesis. The page on which each one is defined or first used is also given.

Abbreviation	Meaning
ANOVA	Analysis of variance.....46
CBT	Cognitive-behaviour therapy/treatment.....30
CPRS	Comprehensive Psychopathological Rating Scale .....39
DSM	Diagnostic and Statistical Manual .....9
EE	Expressed Emotion.....14
FMSS	Five Minute Speech Sample.....44
GT	Grounded theory.....47
ICD	International Statistical Classification of Diseases.....149
MADS	Maudsley Assessment of Delusions Schedule.....11
PCT	Personal Construct Theory.....135
SPSS	Statistical Package for the Social Sciences.....46
SO	Significant Other (Relative, carer or friend).....33

## List of Figures

<b>Figure 2.1:</b> Flow diagram showing systematic review process.....	21
<b>Figure 3.1:</b> Recruitment procedure of patients.....	38
<b>Figure 3.2:</b> Triangulation of reports.....	41
<b>Figure 4.1:</b> Recruited sample of patient participants.....	51
<b>Figure 4.2:</b> Relative and staff participants.....	53
<b>Figure 4.3:</b> Summary of interview combinations available for further analysis.....	54
<b>Figure 4.4:</b> Distribution of patient participant preferences of people they nominate as people to whom they speak about their delusions.....	64
<b>Figure 4.5:</b> Overall global severity of illness (according to CPRS).....	66
<b>Figure 5.1:</b> A model of the patients' experiences of communications about their delusions.....	112
<b>Figure 5.2:</b> A model of relatives' communication with patients.....	121
<b>Figure 5.3:</b> A model of staff communication with patients.....	129



## List of Tables

<b>Table 2.1:</b> Studies of routine communication about delusions.....	28
<b>Table 4.1:</b> Relatives to whom patients spoke about their delusions.....	56
<b>Table 4.2:</b> Staff to whom patients spoke (nominated) about their delusions.....	59
<b>Table 4.3:</b> Summary of whether patients nominated a confidant (about delusions) or not according to demographic and illness characteristic.....	63
<b>Table 4.4:</b> Overall global severity of illness (according to CPRS).....	65
<b>Table 4.5:</b> Characteristics of all patients according to depression subscale- CPRS and their ability to nominate.....	67
<b>Table 4.6:</b> Patient reported psychotic symptoms as rated on the CPRS and ability to nominate a confidant.....	69
<b>Table 4.7:</b> Patient's ability to nominate someone according to the affective impact of their delusion.....	72
<b>Table 5.1:</b> Stages of grounded theory.....	101
<b>Table 5.2:</b> Categories of communication about delusions according to the patients' narratives.....	103
<b>Table 5.3:</b> Categories identified in the relatives' narratives On the most important delusion.....	114
<b>Table 5.4:</b> Categories identified in the staff narratives on the delusion.....	123

# Chapters

<b>CHAPTER 1: INTRODUCTION.....</b>	<b>1</b>
1.1 Background.....	2
1.1.1 Everyday communication and its importance.....	2
1.1.2 Everyday communication with people with psychosis.....	2
1.1.3 The nature of delusions.....	4
1.1.4 Working definition of delusion.....	5
1.1.5 Types of delusion.....	7
1.1.5.1 Functional or organic	
1.1.5.2 Monothematic or polythematic	
1.1.5.3 Primary or secondary delusions	
1.1.5.4 Bizarre or non-bizarre	
1.1.5.5 Content of delusion	
1.1.6 Formation of delusions.....	10
1.1.7 The assessment of delusions.....	11
1.1.8 Acting on delusions and its relevance	
1.1.9 The assessment of social interactions and social climate between people with psychosis and those with whom they routinely talk about delusions.....	14
1.2 Aims.....	16
1.3 Hypotheses.....	17
 <b>CHAPTER 2: LITERATURE REVIEW; ROUTINE CONVERSATIONS ABOUT DELUSIONS.....</b>	 <b>18</b>
2.1 Specific aims and research questions for the systematic review.....	19
2.2 Review methods.....	19
2.2.1 Search strategies.....	19
2.2.2 Study inclusion criteria.....	20
2.2.3 Study exclusion criteria.....	20
2.2.4 Data extraction and analysis.....	21
2.3 Results.....	22
2.3.1 Papers retrieved.....	22
2.4.2 The studies on everyday (non-therapeutic) communication about delusions	

2.4 Discussion.....	29
2.5 Conclusions after the systematic review.....	30
<b>CHAPTER 3: METHODS.....</b>	<b>31</b>
3.1 Research ethics approval.....	32
3.2 Ethical considerations.....	32
3.2.1 Informed consent.....	32
3.2.2 Confidentiality.....	33
3.2.3 Comfort.....	33
3.3 Overview of study design and choice of study participants.....	33
3.4 The Samples.....	34
3.4.1: Inclusion criteria for participation.....	34
3.4.1.1 Patient participants	
3.4.1.2 Informant participants: Relative/Friend (Significant Other)	
3.4.1.3 Informant participants: Staff	
3.4.2. Exclusion criteria of patient participants.....	35
3.5 The procedures.....	36
3.5.1 Recruitment procedures.....	36
3.5.2 The interview procedures.....	39
3.6 Measures and Instruments.....	42
3.6.1 Patient participants.....	42
3.6.2 Informant participants.....	43
3.6.3 The narratives.....	44
3.7 Data management.....	45
3.7.1 Power calculation.....	45
3.7.2 Data entry.....	45
3.7.3 Data analyses.....	46
3.7.3.1 Quantitative data analysis	
3.7.3.2 Qualitative data analysis	
<b>CHAPTER 4: RESULTS.....</b>	<b>47</b>
4.1 The samples.....	49
4.1.1 Patient participants.....	49
4.1.1.1 Prevalence of talking about delusions	
4.1.1.2 Identifying the patient groups in terms of their talking about their delusions	

4.1.1.3 Relatives and staff to whom patients speak about their delusions and who they nominate to speak with researchers	
4.1.2 Relative participants.....	54
4.1.3 Staff participants.....	57
4.1.4 General and historical characteristics of all study patients.....	60
4.2 Patients preferences for person to whom they talk about delusions.....	64
4.3 Variables associated with the ability to nominate a confidant.....	65
4.3.1 Illness severity and nomination of a confidant.....	65
4.3.2 Patient reported psychotic symptom and nomination of people to whom they spoke about their delusions.....	68
4.3.3 Affective impact of the patient's most important delusion and the ability to nominate a confidant.....	71
4.3.4 Violent acts associated with the most important delusion and the ability to nominate.....	73
4.3.5 Content of delusion (MADS rated) and ability of patients to nominate confidants.....	73
4.3.6 Summary of the patient characteristics, including properties of their <i>most important beliefs</i> , which affect their ability to nominate people they can talk to about that belief.....	74
4.4 Agreement and disagreement between patient, relative and staff perceptions of the most important belief and its characteristics.....	75
4.4.1 Patient preferences in talking with others about beliefs.....	75
4.4.2 Perspectives on delusion content.....	79
4.4.2.1 The relationship between the patient's free account of his/her belief content and content elicited by more structured eliciting of delusions by content	
4.4.2.2 Comparison of patient and observer perspectives on the most important belief	
4.4.3 Patient, relative and staff perspectives on degree of conviction about the most important belief and belief maintenance factors.....	82
4.4.4 Patient and observer perceptions on affect relating the chosen belief	
4.4.4.1 The various perceptions on negative affective impact of the most important belief.....	83

4.4.4.2 The various perspectives on positive emotions attributed to the patient-designated most important belief	
4.4.5 Perspectives on actions on beliefs.....	86
4.4.5.1 Assertive, outwardly directed actions on beliefs and harmful actions	
4.4.5.2 Withdrawal actions on beliefs	
4.4.6 Summary of congruence and dissonance in patient, relative and professional staff descriptions of the patient-designated most important belief and its consequences.....	93
 <b>CHAPTER 5: A MODEL OF HOW PATIENTS, NOMINATED RELATIVES, AND PROFESSIONAL STAFF UNDERSTAND THE PATIENT'S MAIN DELUSION.....</b>	<b>94</b>
5.1 Introduction and aims.....	95
5.2 Methods.....	95
5.2.1 The sample.....	95
5.2.2 Source and data collection of narrative.....	95
5.2.3 The interviews.....	96
5.2.3.1 Patients	
5.2.3.2 Significant others (Relatives and Staff)	
5.2.4 Analyses.....	99
5.3 Results.....	102
5.3.1 Categories pertaining to patients' communication.....	102
5.3.2: The emergent model of patients' communication about delusions.....	110
5.3.3 Categories of relatives' perceptions of communication with the patient..	113
5.3.3.1: Narratives about the 'most important' delusion	
5.3.3.2: Additional narratives about the 'most important' delusion	
5.3.4 A model of relatives' perceptions of communication with the patient.....	119
5.3.5 Categories of staff perceptions of communication with the patient	
5.3.5.1: Narratives about the 'most important' delusion.....	122
5.3.6 A model of staff perceptions of communication with the patient.....	127
5. 3.7 Congruence and dissonance between the three emergent models.....	123
5.3.8 Preliminary testing of models with reference to the literature.....	131
5.3.8.1 Resistance of delusions to confrontation with reality	
5.3.8.2 Self-reinforcing aspects of delusional ideation	
5.3.8.3 Other interventions to modify delusions	
5.3.8.4 High expressed emotion in relatives and staff	
5.3.8.5 Implications for practice and future research	

<b>CHAPTER 6: DISCUSSION AND CONCLUSIONS.....</b>	<b>143</b>
6.1 Summary.....	144
6. 2 Talking about delusions with others and ability to nominate.....	146
6.3 Willingness of nominees to speak about delusion.....	148
6.4 Congruence and dissonance between the parties in reports of the nature of the delusion.....	152
6.4.1 Similarities and differences in perception of affective impact of the most important delusion.....	153
6.4.2 Recognition of harmful behaviours on self and other people	
6.5 A testable model of understanding communication about delusions.....	157
6.7 Limitations and strengths.....	163
6.7.1 Sample and design method.....	163
6.7.2 Measures implemented in study.....	166
6.8 Implications for clinical practice.....	167
6.9 Implications for future research.....	170
6.10 Conclusions.....	172
<b>REFERENCES.....</b>	<b>173</b>
<b>APPENDICES.....</b>	<b>186</b>
<b>Appendix 1:</b> Performa for data extraction (A Mini-Review Protocol) .....	187
<b>Appendix 2:</b> Research ethics approval (details and letter of approval).....	192
<b>Appendix 3:</b> Research passport form .....	198
<b>Appendix 4:</b> Request letter by the project leading figure to all consultant psychiatrists seeking participation and permission .....	203
<b>Appendix 5:</b> Follow up communications for consultant psychiatrists participation in the study.....	205
<b>Appendix 6:</b> Advertisement pposters for the recruitment procedure.....	210
<b>Appendix 7:</b> Participant information sheet about the study.....	212
<b>Appendix 8:</b> Consent form for patient participants.....	215
<b>Appendix 9:</b> The University Graduate College Programme.....	216

<b>Appendix 10:</b> Interview organisation and data collection between researchers.....	218
<b>Appendix 11:</b> The Comprehensive Psychopathology Rating Scale (CPRS).....	219
<b>Appendix 12:</b> The Maudsley Assessment of Delusions Schedule (MADS)-Patient's version.....	237
<b>Appendix 13:</b> Demographic, clinical and historical data completed from case notes/electronic database.....	249
<b>Appendix 14:</b> The Maudsley Assessment of Delusions Schedule (MADS) – Informant's version.....	250
<b>Appendix 15:</b> The Maudsley Assessment of Delusions Schedule (MADS) – The informant interview.....	261
<b>Appendix 16:</b> Example of verbatim transcriptions of staff FMSS.....	263
<b>Appendix 17:</b> Characteristics of patients, with details of whether and who they nominated as people they spoke to about their delusions.....	265
<b>Appendix 18:</b> Difference in nominations between those with a diagnosis of schizophrenia and patients with any other psychosis.....	266
<b>Appendix 19:</b> Characteristics of all patients according to depression subscale-CPRS and their ability to nominate.....	267
<b>Appendix 20:</b> Number of symptoms according to CPRS (depression subscale) and their ability to nominate.....	268
<b>Appendix 21:</b> Number of psychotic symptoms (CPRS) reported by the patients and ability to nominate.....	269
<b>Appendix 22:</b> Difference in negative (terrified, angry or sad) affective impact reported and ability to nominate.....	270
<b>Appendix 23:</b> Patients ability to nominate someone according to violence relating to their delusion.....	271
<b>Appendix 24:</b> Patients ability to nominate someone according to violence reported by nursing staff.....	272
<b>Appendix 25:</b> The ability of patients to nominate someone according to their delusion content.....	273
<b>Appendix 26:</b> The MADS – Preliminary coding of items for informants' comparison table.....	274
<b>Appendix 27:</b> The MADS – Informants' comparison table.....	282

<b>Appendix 28:</b> Comparison table of delusion type (derived by MADS free narrative description of patient's most important belief) between patients, relatives and staff.....	300
<b>Appendix 29:</b> Frequency of the most important delusion type (derived by CPRS).....	218
<b>Appendix 30:</b> Table of 'coded' delusion type and its frequency (derived by CPRS).....	320
<b>Appendix 31:</b> Outgoing and withdrawal behaviour driven by the patient's most important delusional belief: Derived from (MADS).....	321



# **Chapter 1:**

## **Introduction**

## **1.1 Background**

### **1.1.1 Everyday communication and its importance**

The ability to communicate effectively is essential for all social animals. Without communication, there is no way to express thoughts, ideas, feelings and needs. Human beings have many ways of communicating, with verbal language regarded as the most typical of humans and, in many ways their most important form of communication. It is verbal communication that is the core interest in this study.

### **1.1.2 Everyday communication with people with psychosis**

What do people with psychosis talk about with other people? What do people who have psychotic symptoms choose to say to people who do not have psychotic symptoms, and does it matter whether these others are relatives or friends or mental health professionals? Do they talk about everyday matters in the context of psychotic symptoms? Do they talk about their psychotic symptoms?

Life intrudes on illness - even the most persistent of the positive symptoms - delusions – are said rarely to be constantly present. At any rate, many patients do think and talk about matters other than their symptoms. Among 48 chronically ill patients Myin-Germeys and colleagues (2001) sampled various time frames throughout the day in order to estimate how much of their time was spent in delusional experiences. They found that, on average, about two-thirds of the time was spent on something other than delusions. Other matters included:

- Dealing with daily problems
- 'Helpful' interventions by others
- Concern that one's life is in the hands of other people
- Emotional climate in family settings
- Vulnerabilities in other community settings

This, however, meant that, on average, about a third of the patients' waking time was spent with their delusions. Such time was associated with more experience of negative affect and less positive feelings. Presence of acquaintances or family members reduced the chance of experiencing the delusions. The authors say that the patients rated the presence of these others as 'moderately pleasant', but they give no other information about how they interacted or any hint of content in what they may have said to each other. Might they have spoken about their beliefs, and perhaps, if only temporarily found some relief in not being alone with them? If so, what are everyday communications about delusions between a person with such beliefs and their family members or friends like? Are they similar to or different from such conversations between a person with delusions and their doctors, nurses or other clinical staff? By 'such conversations' I do not mean the highly structured communications of questionnaires or cognitive behavioural therapists, but rather the more everyday exchanges in the outpatient clinic or on the inpatient ward, when the patient makes the first conversational move or where the question from the clinician is an open inquiry about the patient's wellbeing, health or progress.

An interest in such issues is important, because people with delusions may themselves have concerns about what they may say about them, their relatives and friends and acquaintances may have concerns about how to respond. A quick search through Google, reveals a weight of questions from acquaintances, friends or relatives seeking guidance on this point – and a good deal of unsubstantiated

advice. While some early evidence for clinicians, from a very small number of cases, appeared to support the benefits of suppressing talk about delusions among people with chronic schizophrenia (Wincze et al, 1972; Liberman et al, 1973), current wisdom is that clinicians generally, and not only cognitive behavioural experts, should facilitate discussion of delusions (Freeman & Garety, 2006). Certainly, clinicians need to have a good relationship with their patients and the availability of accurate information about symptoms is important in order to make a diagnosis and good treatment decisions. Medication, although generally a fundamental part of treatment, is only one factor in helping people with psychosis to become well and to rebuild their lives. The therapeutic relationship between people with psychosis and their mental health professionals is integral to the recovery process and influences the outcome of the illness (Ivezic et al., 2001). Good professional–patient relationships, inevitably founded in good communications, have been found to predict positive treatment outcome across a range of treatment settings (Martin et al., 2000) and enhancing the quality of professional– patient communication may be particularly important in successfully engaging patients who are known as difficult to engage (Tehrani et al., 1996). Talking about delusions specifically, however, during routine outpatient appointments still appears to make psychiatrists uncomfortable (McCabe et al, 2002).

### **1.1.3 The nature of delusions**

Beliefs, by definition, require some sort of acceptance that a proposition is true in the absence of evidence for it. People without beliefs of any kind would generally be regarded as unusual. Most people hold beliefs, often religious or political. Generally these are tolerated in an open society, but throughout history there have been instances of persecution of apparently normal people because they hold beliefs that

are not acceptable to the dominant religious or political group, and therefore dealt with as if they were idiosyncratic or false (Taylor, 2006; see, e.g., Mackay, 1869). In turn, people with beliefs that might be regarded as normal, at least to the extent that they have been widely accepted in society, have acted on those beliefs in ways that may be regarded as outside any concept of normal responses

Truly pathological beliefs, called delusions, are common, presenting in a wide range of conditions (Maher & Ross, 1984) and whilst presentations vary greatly, they may occur at some point in over 90% of those diagnosed with schizophrenia. A delusion is one of the most intriguing psychopathological phenomena and its conceptualisation remains the subject of debate. Delusion has always been a central topic for psychiatric research with regard to aetiology, pathogenesis, diagnosis, treatment, and forensic relevance. It is a key clinical indicator of psychosis and has particular salience for the diagnosis of schizophrenia. Although an important element of many psychiatric diagnoses, the definition still seems to be evolving. Some argue that there can be no valid definition of delusion, because people with a delusion are likely to hold this belief with the same conviction and intensity as they hold non-delusional beliefs (Spitzer, 1990; David, 1999).

#### **1.1.4 Working definition of delusion**

Whatever the conflict of ideas and debate on what a delusion may be, some pragmatic, working definition of a delusion has to be adopted in order to progress at all with research. Since the 16th century, delusions have been conceptualised as judgments, beliefs, or ideas that are pathologically false and impossible (Mojtabai, 2000). Jaspers (1913), who was one of the pioneers of modern phenomenology, suggested three main criteria: certainty (held with complete conviction), falsity of

content (implausible, bizarre or patently untrue) and incorrigibility (not changeable by compelling counterargument or proof to the contrary).

Definition has, in practice, changed little since even though each of the criteria has been challenged. It is beyond the scope of my research to discuss this in detail but, in brief, some studies have shown that delusions vary in intensity over time. Garety & Hemsley (1994), for example, showed that the degree of belief conviction and preoccupation could vary considerably over a period of weeks. Moreover, recent studies such as Appelbaum et al (2004) noted that delusions may change over as little as 10 weeks, although it has to be kept in mind that he was referring to patients in treatment and recently discharged from hospital. A crucial point here is that psychotic delusions of any given individual may or may not vary with the course of illness. Whether remission is natural, as it may be with depressive illnesses, or in response to treatment, this does not remove the fact that the delusion was fixed and incorrigible for the period of illness.

The matter of falsity is more confusing. A delusion does not necessarily have to be patently untrue or from incorrect inferences about external reality (Spitzer, 1990), and I have already introduced the difficulty that some religious beliefs which would not ordinarily be held to be delusional are not falsifiable and may sometimes appear similar to psychotic delusions (Young, 2000). In addition, in our clinical practice as mental health professionals, a delusional belief may turn out to be true. Delusional jealousy, for instance, where a person believes that their partner is being unfaithful may have had no initial foundation in fact observable to anyone else at all, but it is not uncommon, finally, for the partner to leave the morbidly jealous person to be with the presumed seducer (Mullen & Maack, 1985). The delusion does not cease to be a delusion because the content is a reflection of reality or becomes true at a later date. Conversely, however, Maher (1988) showed that psychiatrists rarely

have the time or resources to check the validity of a person's claims, leading to some true beliefs to be erroneously classified as delusional, so a delusion may be falsely recorded when a reported description of events seems to the psychiatrist to be patently untrue, but is factual. A well reported case is that of Martha Mitchell, the wife of the Attorney General in the USA who alleged that illegal activity was taking place in the White House. Her claims were first taken as signs of mental illness, and only after the Watergate scandal broke was she proved right (Maher, 1988).

Others have invoked the processes by which delusions may be formed as evidence of their pathology. Kraepelin (1905), for instance, in the ninth edition of his textbook, defined delusional ideas as pathologically derived errors, not amenable to correction by logical proof to the contrary. Stoddart (1908) wrote that a delusion is a judgment which cannot be accepted by people of the same class, education, race and period of life as the person who experiences it. Hamilton (1978) defined delusion as 'a false, unshakeable belief which arises from internal morbid processes. It is easily recognisable when it is out of keeping with the person's educational and cultural background' (see also paragraph 1.1.6 below).

Kräupl Taylor (1979) had perhaps the most useful solution to the dilemma of distinguishing between what he referred to as 'normal delusions' and 'psychotic delusions'. 'Normal delusions' he suggested are those beliefs which are only held to be false or abnormal by someone of another culture, political persuasion or religion. 'Psychotic beliefs' are idiosyncratic, incorrigible, ego-involved and pre-occupying.

### **1.1.5 Types of delusion**

#### ***1.1.5.1 Functional or organic***

Delusions have been classified by presumed aetiology into functional and organic, but this distinction is regarded by now as most outdated. Organic was used to describe delusions thought to be the result of brain damage whereas 'functional' was used when there was no known organic cause. Today, it seems likely that there is a structural or functional brain deficit that underlies most if not all delusions (Kumari et al., 2012). Johnstone and colleagues (1988) reported very little difference between the phenomenology and symptomatology of delusions that were once divided into organic and functional.

#### ***1.1.5.2 Monothematic or polythematic delusions***

A useful distinction can be drawn between "polythematic delusional systems" and "monothematic delusions." Someone exhibiting a polythematic delusional system exhibits a wide variety of delusions covering many different topics. Someone exhibiting a monothematic delusion possesses just a single delusional belief or, at most, a few such beliefs all related to a single theme. Polythematic delusional systems are often noted in people diagnosed with schizophrenia. In contrast, a person presenting with Capgras syndrome, for instance, has the single belief that someone emotionally close, typically a spouse, has been replaced by a complete stranger who, while being a very clever reproduction, is not the much loved person. Other examples of monothematic delusional states include Cotard's syndrome, Fregoli delusional disorder, De Clerambault's syndrome, Othello syndrome (Coltheart et al., 2007).

#### ***1.1.5.3 Primary or secondary delusions***

The confusing subject of primary (autochthonous) and secondary delusions requires some explanation. It is probably most meaningful to use the term primary to imply that the delusion is not occurring in response to another psychopathological form



such as mood disorder or hallucination. A secondary delusion is used in the sense that the false belief appeared to follow on from the pervasive mood state or to provide an 'explanation' for hallucinations. The traditional way of distinguishing primary from secondary delusions is based on the notion that primary delusions 'arise out of nowhere' (Jaspers, 1963).

Wernicke (1906) formulated the concept of an autochthonous idea, an idea that is 'native to the soil', 'aboriginal', arising without external cause. The trouble with finding supposed autochthonous or primary delusions is that it can be disputed whether they are truly autochthonous. Hence, they are not considered as first rank Schneiderian symptoms. It is too difficult to decide in many cases whether a delusion is autochthonous. Several writers have claimed that all delusions are understandable if one knows enough about the patient (Sims, 2003).

#### **1.1.5.4 Bizarre or non-bizarre**

The Diagnostic and Statistical Manual of Mental Disorder, Fourth Edition (DSM-IV; American Psychiatric Association, 1994) treats the presence of bizarre delusions as the heaviest-weighted clinical criterion of schizophrenia. Bizarre delusions are considered to be very strange and totally implausible; an example of a bizarre delusion would be a belief that aliens have removed the reporting person's brain. Non-bizarre delusions are common. One example would be when the affected person mistakenly believes that he/she is under constant police surveillance, and, perhaps particular among offender patients who tend to be naturally paranoid about 'the authorities', there is often a preference for giving the benefit of the doubt to the patient and assuming s/he may be reporting reality. Another example which is difficult for clinicians is when a patient reports concerns about a spouse's fidelity; again, the report may be seen as understandable in the circumstances rather than the delusion it actually is. Thus, it is arguable that there may be clinician bias

against identifying 'ordinary beliefs' as delusions, because there is so much anxiety about where to draw the line with these seemingly ordinary preoccupations.

#### **1.1.5.5 Content of delusions**

In addition to these categories, delusions can be classified according to their content. Delusions are, of course, infinitely variable in details of their content, but certain general characteristics commonly occur. The content is determined by the emotional, social and cultural background of the patient (Sims, 2008). Common general themes include persecution, jealousy, love, grandiose, religious, nihilistic, hypochondriacal and several others.

#### **1.1.6 Formation of delusions**

Various studies have found that there are different routes to delusion formation (Abroms et al., 1966; Magaro, 1980; Brennan and Hemsley, 1984). The route of formation may have implications for how people deal with certain kinds of communication about their belief. Among patients with schizophrenia Hurn and colleagues (2002), for example, found that hypothetical contradiction of belief material had a different effect on the belief(s) under challenge according to the principal mechanism apparently involved in formation of that belief. People who rejected hypothetical contradiction were more likely to regard their beliefs as more "truthful" than those who did not, and had based their delusions primarily on perceptual or hallucinatory experiences. People who accepted the hypothetical contradiction were more likely to have reported that their beliefs affected their behaviour and interfered with their lives and with their thoughts than those who dismissed the contradictions.

The search for brain mechanisms underlying the development and maintenance of delusions has begun (Blackwood et al., 2001) and may yet prove fruitful in further distinguishing subgroups of people with psychosis who can be comfortable with questioning of their beliefs, mediated by one form of brain damage or dysfunction, from those whose delusions are, in effect, a potentially fragile defence against impaired neurological capacity for integrating new, threatening or conflicting information (Taylor, 2006).

Similar encouragement has been offered of a future that may specify dysfunctional recognition, attentional biases, defective memory, reasoning or affective impact as psychological mechanisms and link them to neural systems, but with caution that the cognitive neuropsychiatry of delusions is in its infancy (Gilleen & David, 2005). More sophistication of technique is needed to make links between the nature of delusion formation and brain state.

#### **1.1.7 The assessment of delusions**

Attempts to measure delusions have delivered a wealth of models and scales (Bell et al, 2006), of which none has really been widely accepted as providing a 'gold standard' against which others can be validated. Of these, the Maudsley Assessment of Delusions Schedule (MADS) (Taylor et al., 1994) is one of the most comprehensive. It is an interview based assessment of delusions and built on earlier work by Brett-Jones et al (1987). The MADS is a schedule rated from semi-structured interview covering the phenomenology of abnormal beliefs other than their content, for which other schedules were already well established (e.g. PSE/SCAN) (Taylor et al., 1994). It allows reliable and valid assessment of the delusion which the patient selects as his or her most important belief along nine

dimensions: conviction, belief maintenance factors, affective impact, delusionally driven actions, idiosyncrasy of belief, preoccupation, systematisation, insight, and response to hypothetical challenge. The interview takes around 20 minutes to complete, and previous work suggests that this format is acceptable to the majority of patients. The scale has a very good inter-rater reliability (mean item kappa = 0.82; Taylor et al., 1994).

### **1.1.8 Acting on delusions and its relevance**

The MADS allowed rating of a range of delusion-related actions – some manifestly externally directed, like violence to others, and some in the form of withdrawal – such as avoiding people or ceasing to watch the television. Interest in the attributed link to violence arose because several studies have shown a small but significant association between psychosis and violence (e.g. Arseneault et al., 2000; Fazel, & Grann, 2006). Violence, particularly in its more serious forms, has been repeatedly related to the presence of delusions (e.g. Taylor, 1985; Taylor et al., 1998), so it is important for mental health professionals to be able to get an accurate perspective on what patients are saying about these beliefs. It remains unclear why only some delusions seem to drive violence, and which factors may be important in influencing this association. Some empirical work in the last decade has focused on delusionally driven actions as a relatively common behaviour, contrary to early views, such as Bleuler's 1924 assertion that patients rarely "follow up the logic to act accordingly".

In the first MADS study, however, it became clear that violence was only one type of a range of 'positive', assertive or externally directed actions attributed to delusions. Patients were also likely to report that they had been seeking evidence for their

belief, in some cases that they had found it and, in the majority of cases, that they had been talking to other people about their 'most important belief' (Buchanan et al., 1993). Further, in response to hypothetical challenge - 'Let me suggest something to you that would not fit with your belief ... how you think you would react?' - while some said that it changed nothing, others took the challenge, considered it carefully and then developed their belief, usually simply strengthening it, although in unrelated work, Junginger (1996) was more impressed with the extent of elaboration of beliefs in some patients over time.

Such findings support the notion that, while delusions may be a central component of schizophrenia, the development and/or impact of psychotic symptoms does not occur in isolation, but rather within a social context. Hence, both delusional development and delusionally driven behaviours may be most usefully understood in the context of social interactions.

### **1.1.9 The assessment of social interactions and social climate between people with psychosis and those with whom they routinely talk about delusions**

Families of mentally ill people, and others in their social network, often provide essential support to them, but potent psychological tensions may arise in these families. Leff and Vaughn (1985) demonstrated that that intense emotional over-involvement, with critical and even hostile attitudes towards patients, may be apparent. This had been referred to as high expressed emotion (EE) and has been shown to have a strong association with relapse of the mental illness (Brown, 1962). At its most extreme, this developed into a view that families could cause schizophrenia through the nature of their social interactions (Laing and Esterson, 1964). Kavanagh's (1992) review began to explore the complexities of relationships between illness and EE. There followed a growing understanding that EE tended to arise over time in staff-patient relationships too (e.g. Moore et al, 1992; Berry et al., 2011). The literature on the emotional climate between people with psychosis and their family members and, indeed clinical staff with whom they have long-term relationships continues to grow, but there is very little work exploring the more basic question of how people communicate about their symptoms and how this may be related to emotional climate.

Relatives often find themselves being nurses, social workers or counselors to their ill son or daughter or spouse or parent (Chan, 2010). Some studies have shown that high-EE relatives listen less effectively to the patient and talk more incessantly during family interview whereas low-EE relatives are more prepared to be silent, allowing the ill relatives to express themselves (Kuipers et al., 1983). A major concern of most relatives caring for patients with psychotic illness is that they have no idea how best to talk to their ill relative (Rose, 2006).

In addition, although there is very little information in the previous literature, it seems that when people with psychotic illness talk about their psychotic beliefs, they tend to choose to speak to and/or nominate their relatives as informants about this rather than any other group of people (Wessely et al., 1993). To the best of my knowledge, this study is the only one that has attempted to locate informants who could give detailed information about the patients' delusions in the month before interview. Fifty-nine patients (71%) allowed interview of informants who were actually interviewed; 16 patients did not nominate an informant for interview, while eight patients did so but the informants could not be traced. No informants refused to be interviewed. Informant interviews were conducted blind to the results of the subject interviews. Most informants were close relatives, then social workers and residential hostel workers. For a few patients general practitioners or key nurses were the informants nominated and interviewed.

My research is, therefore, about how patients choose to talk to others about the delusion – the distressing or abnormal belief – which they consider to be the most important, and what they say about it. It is also about how those others to whom the patient speaks about the and the extent to which they have a shared perspective on it. This is important because better understanding the association between talking about delusions and actions consequent upon them, including violence, may offer ways of limiting harm to individual families and acquaintances of those with psychosis, and healthcare staff. Failure to do so could endanger the relationships which might be helpful in supporting an individual's experience of serious mental illness. The results of my investigation could have implications not only for individual patient prognosis and the safety of those around them, but also the potential for informing development of psycho-educational interventions to help families and other people around them.

## 1.2 Aims

1. To find out the likely proportion of people hospitalised with delusions who talk about them with others in ordinary social conversations and/or in routine clinical exchanges taking three perspectives: the people with psychosis, their nominated relatives/friends and their nominated clinician. By routine clinical exchange, I mean clinical conversations outside the structured therapeutic approaches to modify the illness, such as cognitive behavioural therapy.
2. To investigate to whom they prefer to speak about them.
3. To investigate the extent to which patients are willing to allow a researcher to speak with people to whom they speak about their delusions (ability to nominate a relative or staff to talk about them and their beliefs).
4. To explore relationships between characteristics of the patient's illness, including the patient-reported characteristics of delusions (content, fixity, affective impact and whether or not the belief leads to actions), and the ability to nominate a confidant.
5. To examine congruence between the parties reporting with respect to the characteristics of the delusion.
6. To understand the core concern about the patient designated most important delusion according to each party independently and to construct a model for understanding communication in relation to the delusion designated by the patient as his or her most important belief, according to each party independently.



### 1.3 Hypotheses

1. It is more likely that people with delusions will *prefer* to speak about them to relatives than clinical staff.
2. Those people who cannot nominate a relative/any confidant will be more likely to have been (in the last 28 days):
  - 2.1 rated as more ill
  - 2.2 self-rated as more depressed
  - 2.3 made frightened, angry or sad by their delusions;
  - 2.4 acted violently on their delusions.
3. There will be agreement between the three parties (patients and relative or patients and staff) on some key aspects of delusions but less agreement on others such as:
  - a. having delusions with negative affective impact;
  - b. acting violently on their delusions;
  - c. self-harming behaviours

**Chapter 2:**  
**Routine Conversations about Delusions:**  
**A Systematic Review**

## **2.1 Specific aims and research questions for the systematic review**

My aims were to identify and critically review published literature on how and how often people with delusions *routinely* communicate about their delusions in their chosen social circle or with their clinicians, and with what effects. More specifically, my research questions were: what proportion of people with delusions choose to talk to others about them? Where so, how frequently does this happen? To whom do they talk? What do they say? Do patients and listeners report the same things about the conversation? What consequences of talking about a delusion have emerged, including changes in the delusion, in affect about the delusion, in relationship qualities, or actions, including violent actions on the delusion?

## **2.2 Review methods**

### **2.2.1 Search strategies**

First, the Cochrane database and the Database of Abstracts of Reviews (DARE) were examined for any similar reviews. Secondly, three bibliographic databases were searched from their inception (MEDLINE 1950, EMBASE 1974, PsycINFO 1806) until September 2012, using the search terms: 'psychosis', 'psychotic symptoms', 'schizophreni\*', 'delusion\*', or 'false beliefs' cross referenced with the terms 'communication', 'social interaction', 'conversation' or 'talking'. Retrieved titles were scanned for duplicates using EndNote reference management software. Thirdly, the journals *Psychological Medicine*, *British Journal of Psychiatry*, *American Journal of Psychiatry*, *Psychiatric Services*, *Schizophrenia Bulletin* and *The Journal of Clinical Psychiatry* were hand searched in full text from 1<sup>st</sup> January 2000 until

30th September 2012, as a check on whether relevant studies could have been missed. By definition, I was reading all titles in these journals, so for any title that was at all relevant to the topic, the abstract was also read, to provide a check on our selection of search terms. Fourthly, these searches were supplemented with reference list follow-up, and finally grey literature was searched using Google scholar and the abstracts of theses database ([www.theses.com](http://www.theses.com)).

### **2.2.2 Study inclusion criteria**

Studies of adults (aged 18 or over) were included if there was a quantitative or qualitative measure of delusions, whether or not they had become psychiatric patients, and a measure or systematic description of the person talking to others about his/her delusion. No study design was excluded providing the delusion(s) and the communication about them had been systematically recorded. Recording was rated as acceptable and the study included either if recognised rating scales had been used or if verbatim accounts had been recorded and a robust qualitative methodology used to analyse these data. Studies were accepted in any language, providing the title and abstract were in English.

### **2.2.3 Study exclusion criteria**

Studies with people with learning disability and/or gross brain damage were excluded, as were studies with children and adolescents, and studies without a title in English.

#### 2.2.4 Data extraction and analysis

I carried out the electronic search of each database in turn. My supervisor and I reviewed, blind to each other's ratings, 40 randomly selected titles and abstracts generated by the first of these searches, and provided a binary decision: reject or consider for full reading, based on a checklist of the inclusion and exclusion criteria just given, but adding other explicit reasons if necessary. There was full agreement on 38 of the papers (95%); in both cases where there was disagreement, I was the more cautious, and in favour of retrieving the full paper. Thus, after discussion and agreeing the final version of the paper selection *proforma* (see appendix 1 for additional details), I completed article selection alone. This *proforma* proved simple, with three main categories for exclusion: i. not about human conversations but rather about intracerebral communication or gene-environment interactions; ii. the communications studied were not routine but part of structured psychological treatment and/or confined to specific issues such as details of treatment or treatment compliance; iii. a miscellaneous group of other reasons including study of animals other than humans (see also figure 2.1). For the papers selected, data extraction was done independently by both of us according to a *proforma* informed by standardised data extraction tools from the Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instrument (JBI-MASARI). Valid studies proved to be too few and heterogeneous for meta-analysis, so a descriptive analysis is presented.

## **2.3 Results**

### **2.3.1 Papers retrieved**

Findings from the literature search are summarised in figure 2.1. Neither Cochrane nor DARE revealed any previous systematic reviews. The initial search yielded 3,362 titles from the various sources, reduced to 3 after the removal of duplicates and studies which were not, after all, about psychosis or psychotic symptoms or ordinary conversation between a person with delusions and a relative, friend or acquaintance or in a routine clinical consultation. None of the Google Scholar search titles was relevant. Inspection of titles alone led to rejection of 2,282 articles as not relevant for the reasons just given. About two-thirds of the articles were about forms of communication between people with schizophrenia and another person which were irrelevant to our question - for example cognitive testing, or communication over matters other than delusions, such as diet. Most of the rest were not about interpersonal communication at all, but rather about 'neurological communication', that is neuronal activity or interconnections in the brain among people with psychosis or psychotic symptoms, or about gene-environment interactions. Despite clear search criteria, a small number of studies had to be excluded for other reasons, for example they were studies of animals or juveniles or of staff workshops on assessments. The only three studies which were about routine conversations about symptoms between patients with psychosis and another person are shown in Table 2.1. They were diverse in method and perspective.

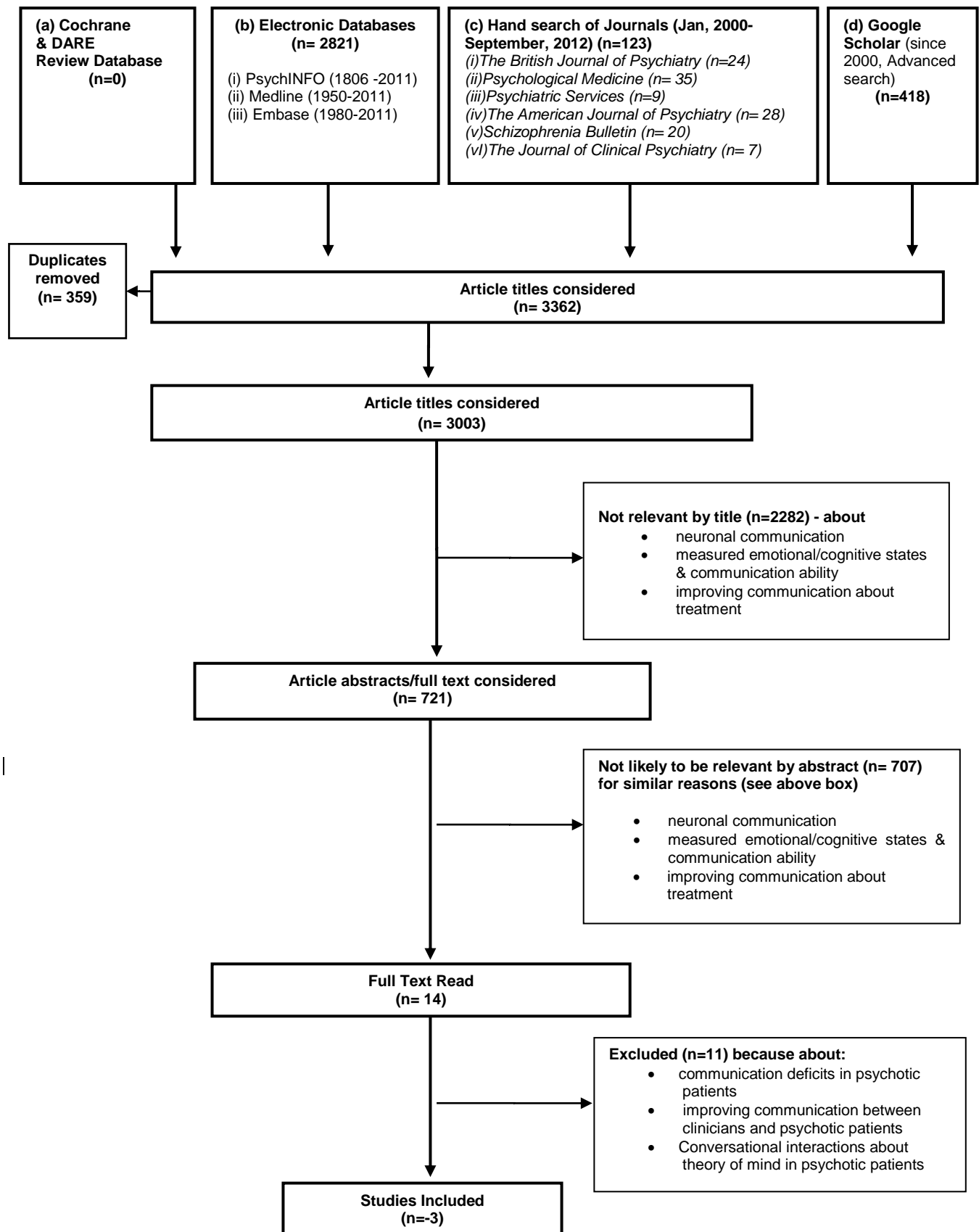


Figure 2.1: Flow diagram showing review process

### **2.4.2 The studies on everyday (non-therapeutic) communication about delusions**

The characteristics of the three studies, two from the UK and one from Norway, which fulfilled all criteria are summarised in Table 2.1. The studies used different methods of investigation. Data from the first study, from three reports (Buchanan et al., 1993; Wessely et al., 1993; Taylor et al., 1994), were supplemented from the original database. The study was one of patients with delusions newly admitted to a general psychiatric inpatient bed (Taylor et al., 1994). Almost all of the patient participants (78/83) talked freely and in detail to the researcher about their beliefs, data on ordinary social communications about these beliefs was collected from both patient reports and the reports of the person the patient nominated as his/her confidant - usually, but not invariably a relative. Just over three-quarters of the patients (61, 78%) reported that they had spoken to at least one other person about their delusions in the previous 28 days. At a second interview, about five days after the first, 32 of the 58 patients (55%) said that they continued to talk about their delusion at the same rate, three people started to talk about the delusion for the first time and five said that had stopped talking about it and 10 (17%) said that they were still not talking to anyone about their delusions. There was no information about the effect, if any, of these routine communications, but the researcher tested the effect of a rather structured response. The patient was asked to consider how they would regard his/her belief if something, which the researcher specified according to the delusion, went against that belief- a hypothetical challenge. Most said that it would make no difference, but a quarter of the sample incorporated the suggestion into the delusion or expressed an increase in conviction about their belief (Buchanan et al., 1993) more of those who said that, in this context, they were even more sure about the belief had been violent than of those who disregarded the challenge.



The second study (McCabe et al, 2002) was an observational study of patient-clinician interactions in a routine outpatient setting. The patients spent very little time talking about their psychotic symptoms to the psychiatrist – an average of 67 seconds per 15 minute sessions. Talking about the symptoms was as likely to be initiated by the patients (22 times) as by the clinician (21 times), with an accompanying carer having raised the matter on just one occasion. Some of the patients clearly said that telling others, including their psychiatrists, about these symptoms was problematic. Nevertheless, they attempted to discuss their psychotic symptoms and sought information about the nature of these experiences and their illness, but ‘when patients did succeed in raising the topic of their concerns [about symptoms], it was often a source of tangible interactional problems.’ There was no information about the effects, if any, of these conversations on symptoms or behaviour.

The third study (Lore & Hem, 2012) method was different again - qualitative work with a range of clinicians about their experiences of communication with patients with psychosis. Thematic analysis was applied and three main themes emerged as shown in Table 2.1. They examined how experiences of people with mental illness are perceived by their clinical staff through communication, and how insight affects assessment of their perspective and involvement. They found that lack of insight gives rise to problems concerning communication. This study was based on in-depth interviews with 11 mental health-care workers which took place at various clinical settings in three different locations in Norway. They discussed different topics with the participants such as lack of insight, awareness of illness, and coping strategies, as well as how these factors affected treatment, cooperation, and participation. The participants described attuned understanding as another-oriented process, involving sensitivity to many aspects of the person’s situation. Understanding is sought and is established through emotional, human contact, and

practical interaction, and ends with newly articulated understanding. The results in this third study suggest that the process described here can be viewed as other-oriented understanding, and not merely sympathy. It is an interdependent process of imagining oneself in the other's place, and depends on awareness of the nature of this process and on sensitivity to the person's expressions

Study	Design	Sample Size	Patient diagnoses	Setting	Measure of communication about delusions	Prevalence of speaking about delusions	Frequency	To whom?	What is said	Responses?
Taylor et al (1994) UK	Longitudinal prospective Interview study with patient and patients nominated confidants	83 (85% of eligible) patients with at least one delusion  58 with two interviews  47 men: 33 women; mean age 33, range 17-66 59 patient nominated informants	Schizophrenia (62%) affective psychosis (26%) paranoid psychosis 9%	General psychiatric inpatient units	Maudsley Assessment of Delusions Schedule (MADS)	77% (60/78)	In the last 28 days: 41 (52%) often 20 (26%) <1X per week 17 (22%) never	By choice: mostly to a relative or friend; sometimes to a mental health clinician	Describing their self-rated most important delusion	Not explicit, but more inconsistency than not between patients and nominated relatives
McCabe et al (2002) UK	Researcher observations of 15 minute clinical consultations	32 (of 61 eligible, 51%) patients 18 men: 14 women	All schizophrenia / schizoaffective disorder	General psychiatric Outpatient clinic	Conversation analysis Jefferson's orthography analysis of audio-taped & transcribed consultation	All 32 patients in a clinical context	Within the 15 minute sessions:	By definition, to their psychiatrist	Psychiatrists asked about frequency & severity of beliefs	Psychiatrists were avoidant of talking about the beliefs e.g. responding to a question with a question;

	Relative present in 1/3 cases	Mean age 47, range 28-66  7/9 randomly selected male psychiatrists					1.4 times (range 0-4) per interaction  lasted on average 67 seconds		Patients sought to describe their beliefs; some asked why others did not believe them	turning to ask the carer, if present, for his/her account; asking how to respond
Loem & Hem, (2012) Norway	Qualitative study of staff communications	11 staff from various clinical disciplines  Patients with psychosis they choose to talk about	'psychosis'	Various clinical settings in three different locations in Norway	Thematic analysis of in depth interviews with the staff	Not specified	Not specified	Exclusively about patient-staff exchanges about delusions	Quoted examples are all of how the staff responded	Communication themes identified were: - Know you do not understand - Emotional contact - Finding meaning and interacting

**Table 2.1: Studies of routine communication about delusions**

## 2.4 Discussion

The most important finding was the dearth of research into talking about delusions within the usual social circle of the person with delusions or during routine clinical exchanges. This is surprising because there appears to be a need for guidance.

The three studies found in this review confirmed variously by self-report, direct observation and staff report that most patients do talk about their symptoms of psychosis, including delusions. Further, entering 'talking about delusions' into Google generates over four million results and 'responding to delusions' well over a million. While these numbers include duplicates, some applications of the concept of delusions that have nothing to do with mental illness, and a large number of general accounts of what delusions are, about 10% of the entries were from people seeking advice about how to respond to relatives or acquaintances with delusions and/or from others giving it.

Advice to relatives and friends comes from a wide range of lay people who are passing on their own experience and wisdom, through people who present as professionals, sometimes within an official website indicating their profession, to clearly professed expert guidance from such bodies as the Canadian Mental Health Association ([http://www.cmha.bc.ca/files/6-hallucinations delusions.pdf](http://www.cmha.bc.ca/files/6-hallucinations%20delusions.pdf)). While the advice generally appears to have acceptable face validity, with a good deal of common ground in neither 'attacking' the delusion nor 'subscribing to it', there is little evidence base for any guidance.

Academic articles and books tend to be bolder. Freeman and Garety (2006) consider that there has been a shift from discouraging people from talking about their delusions to making time for them to do so, and using cognitive behavioural

treatments (CBT) to reduce stress. Turkington and colleagues (2009) in their book for patients and their lay carers also encourage this, not only explaining the use of CBT, but also offering the reader 'an understanding of how carers can use cognitive therapy to help themselves cope better and become an active participant in their psychotic relative's or friend's recovery.

According to the McCabe studies, this optimism may be premature. Wilcock's (2009) advice in the Turkington book is founded only in clinical anecdote with respect to responding to delusions. It may be helpful for anyone without specific training in CBT to adopt and adapt some of its principles, but the case for doing so is not established. Patient responses to the hypothetical challenge posed by a researcher when they were sufficiently troubled by delusions to have been admitted to hospital indicate one reason for caution in this regard.

## **2.5 Conclusions after the systematic review**

A systematic literature search to answer the question: ***Do people with a delusion routinely talk about it?*** yielded only three studies. This is surprising as these studies suggest that talking about delusions is a common phenomenon. There is, thus, little to guide a new clinical study in terms of numbers needed to answer questions about impact of routine conversations about delusions.

## **Chapter 3:**

## **Methods**

### **3.1 Research ethics approval**

This clinical research study was approved by Multi-Centre Research Ethics Committee (REC ref: 07/HO106/148; see also appendix 2). It was also approved by the following Research and Development Departments: Abertawe Bro Morgannwg University Health Board, Cardiff & Vale University Health Board, Avon and Wiltshire Mental Health Partnership NHS Trust, Partnerships in Care (Llanarth Court Hospital). The research was also reviewed by specialists in the Department of Psychological Medicine at Cardiff University, and sponsored by the University.

### **3.2 Ethical considerations**

#### **3.2.1 Informed consent**

All potential participants were provided with adequate information about the study in a simple language and had the opportunity to discuss any questions and consider their potential participation. The researchers had no direct involvement in the clinical care of the potential patient participants, nor did any other dependent relationship exist which might induce coercion. Also, participation was entirely voluntary, and prospective participants were made fully aware that their decision regarding participation would have no impact whatsoever on their clinical care or treatment or any legal or clinical decisions about them



### **3.2.2 Confidentiality**

The research data were kept completely confidential to the research project and identifying details removed from the data sets stored. It was clearly stated to participants that the content of research interviews would not be disclosed to anyone, including clinical teams, unless they directly indicated a risk of imminent harm to self or others, in which case this information, and only this information would be given to a member of their clinical team. It was also confirmed that publications resulting from this research would include only aggregate or anonymised quotations.

### **3.2.3 Comfort**

Participants were not asked to discuss any topics which would not usually be covered during routine clinical interviews. In the unlikely event that a participant became distressed in the interview, each researcher was required to follow the protocol to terminate the questioning, seek to calm and reassure the participant and, if necessary, help the participant in seeking further support from nursing staff or other key healthcare workers.

## **3.3 Overview of study design and choice of study participants**

The parent study was designed as a longitudinal cohort study, but all the data reported here are from the first interview period, making this a multi-centre cross-sectional interview and record study of communication about delusions between people with psychosis who are experiencing them, their relatives (or significant others) and hospital staff.

### **3.4 The Samples**

Three samples were generated. The primary sample was of participants with a delusion. They were recruited from among all inpatients with a psychotic illness and at least one delusion, who were resident in general and forensic psychiatric inpatient units in one NHS health trust at any time between 1<sup>st</sup> August 2009 and 31st January 2011. All who were regarded by the clinical staff as fitting these criteria and being able to give valid consent were approached, and all who gave valid consent were included. It is worth noting that although I joined this program in January 2009, I was not able to access hospitals and interview patients and other participants until I receive my Research Passport (See appendix 3 for the form) which took around six months. The data collection, therefore, started in August.

A second sample of relatives/ carers was recruited after nomination by the patient (primary participant) as the person in his/her chosen social circle to whom s/he was most able to talk to about his/her delusion(s). A third sample of hospital staff participants were preferentially recruited in the same way as the relatives/carers, according to patient recommendation, but where no nomination was made, the patient's primary nurse was invited, with the patient's consent, to participate.

#### **3.4.1: Inclusion criteria for participation**

##### ***3.4.1.1 Patient participants***

- Age 18 years and over
- Experiencing at least one delusion, described to staff for case ascertainment as a false or otherwise pathological belief, and for the decision on inclusion

as an absolute conviction of the truth of a proposition which is idiosyncratic, incorrigible, ego-involved and often preoccupying (Kraupl Taylor, 1979)

- Resident in hospital at the time of ascertainment
- Able to give valid consent for participation in research (as determined by clinical team).

#### **3.4.1.2 Informant participants: Relative/Friend (Significant Other)**

- Age 18 years or over
- Nominated by the consenting patient participant as the most able to talk with about his/her delusion.
- Able to give fully informed consent

#### **3.4.1.3 Informant participants: Staff**

- Nominated by the consenting patient as the most able to talk with about his/her delusion (could include primary nurse), or
- Non-nominated primary nurse
- Consenting

#### **3.4.2. Exclusion criteria of patient participants**

- Acute and transient psychotic disorder.
- Disorders of speech and language, developmental disorders or mental retardation sufficient to impair communication with a researcher, or otherwise not fluent in the English language.

## **3.5 The procedures**

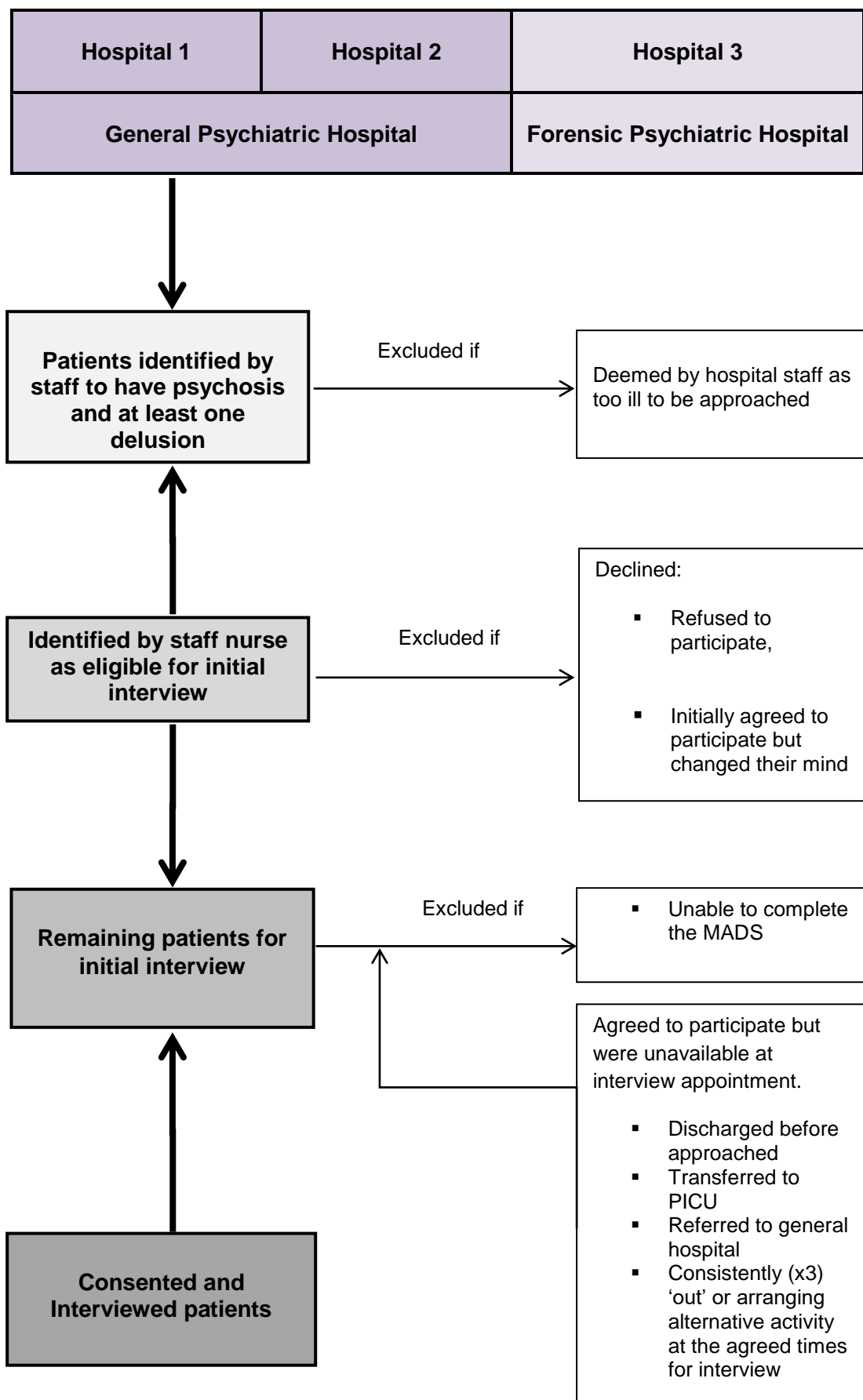
### **3.5.1 Recruitment procedures**

First, I contacted all consultant psychiatrists working in the three hospitals involved to seek permission in principle to approach their patients (See appendix 4 for my request letter and appendix 5 for follow up communications). Then I arranged a meeting with ward managers and senior nurses to set up a liaison strategy with them to facilitate referral of patients potentially eligible for this study. I clearly explained the Inclusion and exclusion criteria, and I designed a poster advertisement to remind the staff of this study and help with the recruitment (Appendix 6). A poster for each ward was displayed in the staff office after relevant permissions had been obtained.

At the initial meeting with a patient, I gave the participant information sheet (see appendix 7) to read and keep, and I talked through the information with the patient. The patient was then invited to ask any questions s/he wished about the research. Once the patient seemed satisfied that s/he had all the information s/he wished, written consent to participation was sought (Appendix 8). Once that had been given, I will arrange a mutually convenient time to return to interview the patient. The reason for not interviewing immediately, although some patients would have preferred that, was that the ethics committee had required a lapse of at least 24 hours between consent and interview.

Interviews were arranged at such times as to avoid interruption in the delivery of normal clinical care for patients, or daily living activities, for example, avoiding designated therapy periods, meal times. Immediately prior to commencement of the first interview, I recheck the consent with the patients, after a further opportunity was

offered to answer any questions they might have. The recruitment process is summarised in figure 3.1



**Figure 3.1: Recruitment procedure of patients**

### **3.5.2 The interview procedures**

All research workers involved in this study, including myself, were trained in each of the semi-structured interviews, using first mock interviews with clinicians in the office. Once reliability had been achieved in terms of 100% agreement on whether a symptom was present to a level constituting pathology or not, the researcher conducted two patient interviews while observed by an experienced interviewer to check that the interview skills could be transferred to the real clinical context. In addition, I have completed other doctoral training program which addressed both academic expertise and personal skills which helped me in developing generic skills and competencies. These skills exceeded the specific topic of the MD and were applicable in a wider context (Further details are shown in appendix 9)

I managed to keep all patient interviews in private place, in a quiet room on the ward. Each interview took between one and half up to three hours to complete, for various reasons, for example aspects of the patient's mental state made him or her distractible, the patient had thought disorder, the patient wanted a break. The interviews and questionnaires were therefore delivered over more than one block of time if necessary, separated by cigarette or tea breaks to reduce fatigue or restlessness. All interviews were, however, completed on the same day.

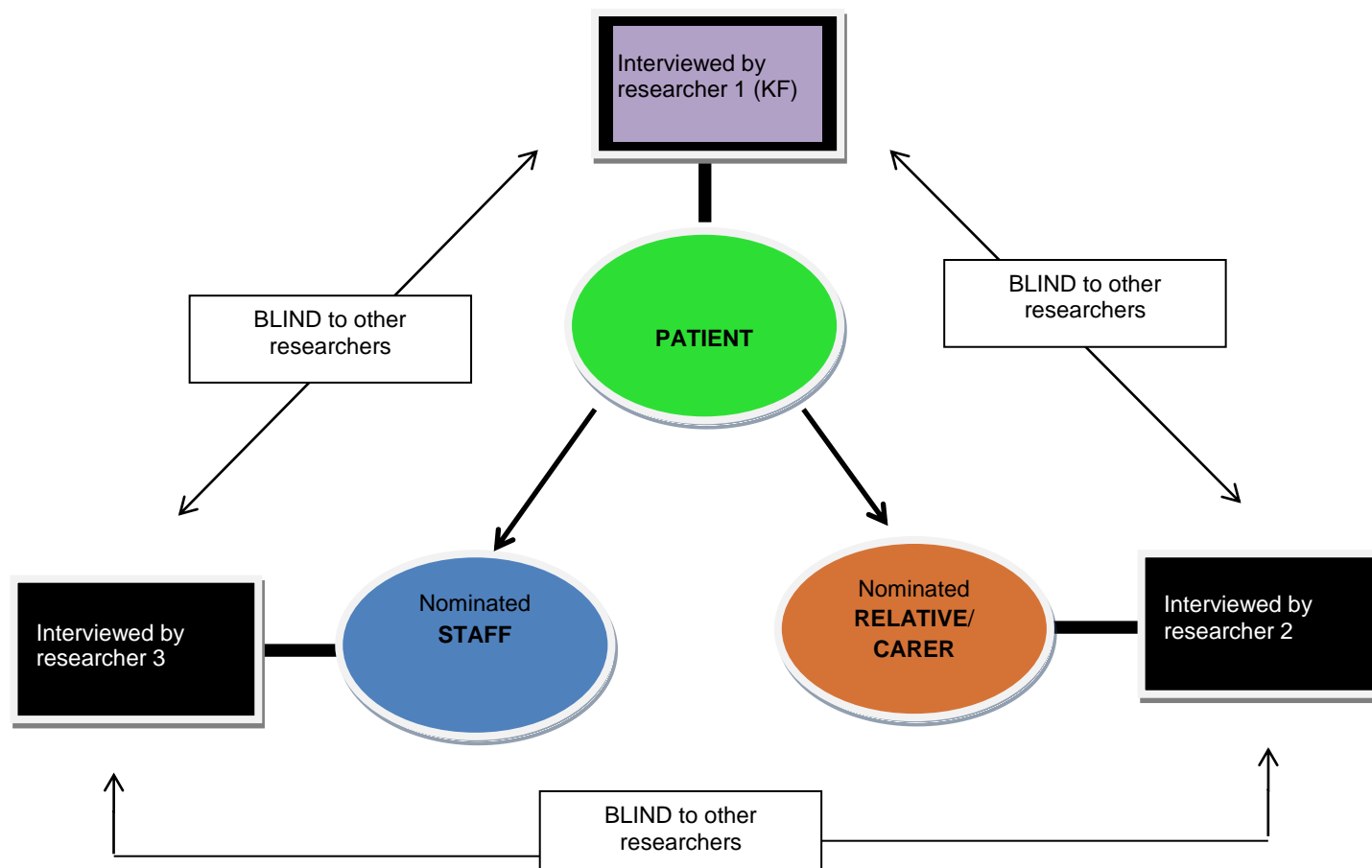
After a few brief demographic questions, I presented the first section of the research assessment; a semi-structured interview about the general mental state - the Comprehensive Psychopathological Rating Scale (CPRS). As part of this, a delusion or delusions were identified. If the patient had just one delusion, that became the centre of more detailed evaluation of the delusion; if more than one

delusion had been identified, the patient was asked to select the one s/he regarded as the most important. As far as possible, I avoided using the word 'delusion' with the patient, as some were offended by any suggestion that they might be regarded as having one, whereas all consenting patients accepted questions about their beliefs.

Details about this belief were elicited using the Maudsley Assessment of Delusions Schedule (MADS), with some additional questions developed for this study particularly to learn about to whom and how they talked about this belief. I extracted from medical records additional data, including history of violence. At the end of the interview, I ask the patients to nominate both a significant other such as a relative/carer and a hospital staff person to whom they could speak about the belief and would be content for us to approach for interview. Formal, signed consent was requested for these approaches. Where the patient was unable to nominate a relative, no further action could be taken. When a patient was unable to nominate a member of staff, permission was sought to approach his or her primary nurse.

As this study constitutes the first part of a larger study of delusions and violence, co-researchers working on other parts of the study interviewed the patient's selected relative/carer and another interviewed the nominated staff member, so that each interviewer was blind to the other accounts except in respect of the patient's choice of most important delusion (See appendix 10 for interview organisation and data collection between researchers). Figure 3.2 also illustrates the triangulation of reports from patients, a nominated relative/friend and a nominated staff.





**Figure 3.2: Triangulation of reports**

## 3.6 Measures and Instruments

### 3.6.1 Patient participants

- ***The Comprehensive Psychopathological Rating Scale*** (CPRS; Asberg et al. 1978) provides a sensitive and reliable assessment of a wide range of psychiatric symptoms, and is easily communicable. 65 scaled items are accompanied by explicit definitions in non-technical language as well as scale steps, and little training is required for raters. Ratings of 0-1 mean that there is no evidence of a symptom at all, or some evidence but not amounting to pathology, while ratings of 2-3 indicate definite pathology, at varying degrees of seriousness. 40 items are ratings of psychopathology reported by the interviewee, and 25 are interviewer ratings of observed psychopathology. In addition, the rater is required to provide a global rating of the illness and an estimate of the reliability of the rating, taking account of the patient's ability to talk coherently, distractibility and so forth (See appendix 11 for further details of the instrument).
- ***The Maudsley Assessment of Delusions Schedule*** (MADS; Taylor et al., 1994) allows reliable assessment of the delusional belief which the patient selects as his or her most important belief along nine dimensions: conviction, belief maintenance factors, affective impact, delusion related actions, idiosyncrasy of belief, preoccupation, systematisation, insight, and response to hypothetical challenge. The interview takes around 15-20 minutes to complete, and previous work suggests that this format is acceptable to most patients. (See appendix 12 for further details).

- The *proforma* for collecting demographic, historical, clinical and offending data from the clinical case records, together with information about any violent incidents which occurred within 28 days prior to the interview is shown in appendix 13.

### 3.6.2 Informant participants

***The MADS informant interview*** is, in effect, a mirror image of the MADS, simply addressing the all questions originally posed to the patient, to the relatives or staff about the patient's belief (See appendix 14 & 16). The one aspect of the interview which was not blinded from the patient-participant's account was the patient's selection of the most important belief. The relative or staff member was first asked what s/he considered to be the patient's selection of belief. If that was in accordance with the actual selection, the interview proceeded with the MADS informant interview. If the patient had selected a different belief, then the interviewer said:

*Thank you. I would now like to talk about one particular belief in more detail, and that is X (i.e. the one the patient has nominated as the most important belief).*

If the observer said that they knew nothing about that one, the researcher recorded that, then said

*Well let me just ask you a few questions about it from my schedule here, in case anything seems familiar or you recall something you hadn't thought special.*

In practice, most observers knew about the belief but had not selected it as the most important.

**Five Minute Speech Sample** (FMSS; Magana et al., 1986), adapted from the brief verbal sample procedure developed by Gottschalk and Gleser (1969). An observer who has known and related to the individual concerned for at least 3 months is asked to speak for five uninterrupted minutes about the individual, covering the following areas, which are placed on a card in front of him/her as an *aide memoire*.

- What kind of person is X?
- How easy is X to get to know?
- What is it like to spend time with X?
- Is there anything X does that you find hard to deal with?
- Is there anything X does that you appreciate?

The narrative is audio recorded and transcribed, allowing a rating of EE according to defined criteria and providing material for qualitative analysis.

### **3.6.3 The narratives**

The narratives were mainly drawn from responses from the three parties to two open questions about the delusions during the MADS interview (Taylor et al., 1994), and, where necessary (e.g. poor description of delusion by some patients), the informant accounts were supplemented from with references to the delusions and communications about them in the free narrative obtained during the five minute speech sample, just described. Verbatim notes were taken during the interview about the delusions, and the narrative written up in full immediately afterwards (for further details, see chapter 5).

## **3.7 Data management**

### **3.7.1 Power calculation**

The parent study, which was about associations between change in psychotic symptoms and violence, calculated the sample size necessary to detect significant differences at the level of probability  $p=0.05$ , and power over 0.80. Pre-study power analysis is important for determining the minimum sufficient sample size for testing a hypothesis, which takes on particular importance if differences are likely to be small and thus there is a high chance that failure to find significant differences postulated could be explained by a small sample size. In this study, however, notwithstanding my attempt to create defensible hypotheses, there was a dearth of data on which to base a power analysis for the more quantitative aspects of the study. Furthermore, a larger sample size could not be obtained during the period available for my data collection as I recruited all eligible patients who presented and who consented to participation during the designated time. I acknowledge, therefore, that my study must be regarded as more exploratory than originally intended. The qualitative findings are not, of course, affected by sample size predetermination.

### **3.7.2 Data entry**

A database was set up for this study. I assisted in doing this, in preparing the meta-data and in checking the accuracy of data entry.

### **3.7.3 Data analyses**

#### **3.7.3.1 Quantitative data analysis**

All quantitative data were analysed using the Statistical Package for the Social Sciences (SPSS) Version 20. Participants and non-participants were compared on a simple data set: sex, age, hospital, length of admission and diagnosis, to check for selection bias. Descriptive statistics were calculated on the general characteristics of the patients, their chosen significant others (SO) and their chosen staff person as well as mental state generally (CPRS) and the main delusion along the nine dimensions of the MADS, according to the patient, relatives and staff.

Where possible, Pearson chi-square tests were used in the comparison of categorical data, but, as the sample size was small, in many comparisons at least one of the cell sizes fell below 5. This meant that I had to apply Fisher's Exact Test (FET) which is the more valid test of the probability that a finding was a true deviation from the null hypothesis. Although the FET works in a similar way to chi-square test, it calculates an exact probability value for the relationship between two dichotomous variables. A one-way analysis of variance (ANOVA) was used for continuous data. In both cases, I made an assumption of normal distribution of data.

My original analysis plan included an intention to apply multivariate statistics to attempt to disentangle relationships between the main outcome, or dependent variable – ability to nominate a confidant – and the dependent variables and test for confounding. Unfortunately, the sample size was too small to permit this, but I have shown in chapter 4 where I would have liked to apply this.

### **3.7.3.2 Qualitative data analysis**

Transcripts of participant narratives were analysed using the grounded theory (GT) method (Glaser and Strauss, 1967; Glaser 1978). Further details are given in Chapter 5.

## **Chapter 4: (Results)**

***Talking about delusions – frequency of doing so, preferences for people to whom patients speak about delusions (confidants), variables affecting ability to nominate and levels of agreement between patients, relatives and staff when apparently talking about the same delusion***



## **4.1 The samples**

### **4.1.1 Patient participants**

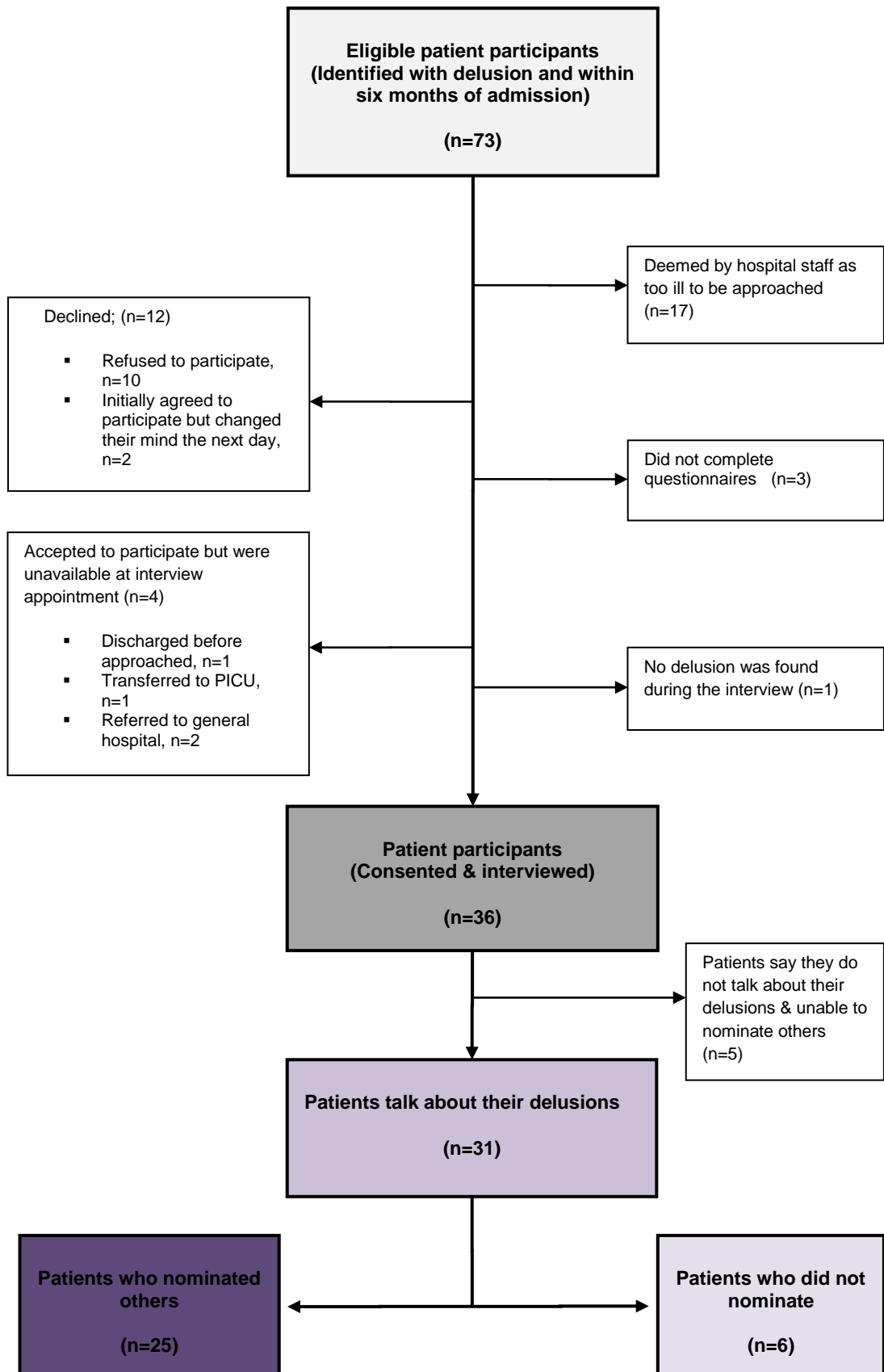
Seventy-three patients, from three different hospital units, met inclusion criteria. Forty-eight were from two general psychiatric hospital units and 25 from one medium security hospital unit. One of the two psychiatric hospital units had 57 beds and the other had 40 beds. The forensic setting was a purpose designed NHS medium security hospital unit with 64 beds. Thirty-seven of the 73 patients were excluded from the study for various reasons: 17 were not approached at the request of nursing or medical staff because they thought they were too ill at the time of interview; 10 patients refused to receive information about the study or any approach from researchers; 11 patients accepted information, but declined to participate having done so; 9 consented and agreed to take part in the study but never completed the interviews for a variety of reasons including 'tiredness', 'boredom' or always having something else to do. One patient appeared to have recovered by the time of interview (further details are shown in Figure 4.1).

#### ***4.1.1.1 Prevalence of talking about delusions***

Thirty-one (86%) of the 36 included patients said that they spoke to others about their delusion, and nominated at least one person to be interviewed.

#### ***4.1.1.1.2 Identifying the patient groups in terms of their talking about their delusions***

Five of the 36 patients said that they had not spoken to others about their delusion. All five of the patients who denied talking with anyone about their delusions, by definition, had mental health staff available to speak with as they were inpatients; in fact, I was able to establish from the records and/or staff reports that they also had family or friends available to speak too as well had they wished to do so. Although this subgroup denied previous conversations about their beliefs, they did speak freely with me or one of the other researchers. A second distinct group was made up of six of the 31 patients who reported speaking to at least one person about their delusions, but who did not wish to nominate the person they spoke to about them as a confident eligible for the research – that is they refused to allow me or a colleague to speak to their confident. Members of this group also appeared to speak freely to a researcher.

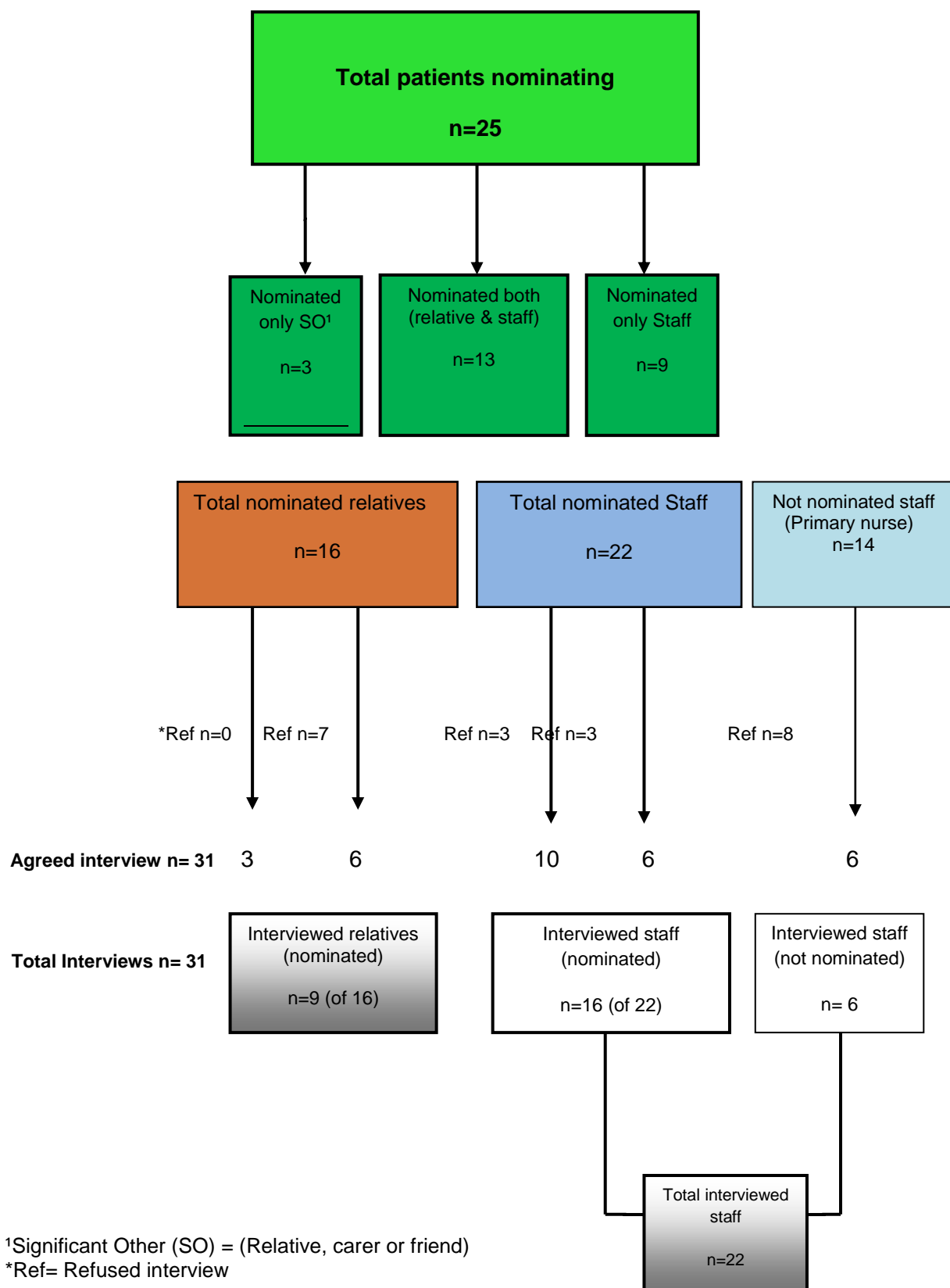


**Figure 4.1: Recruited sample of patient participants**

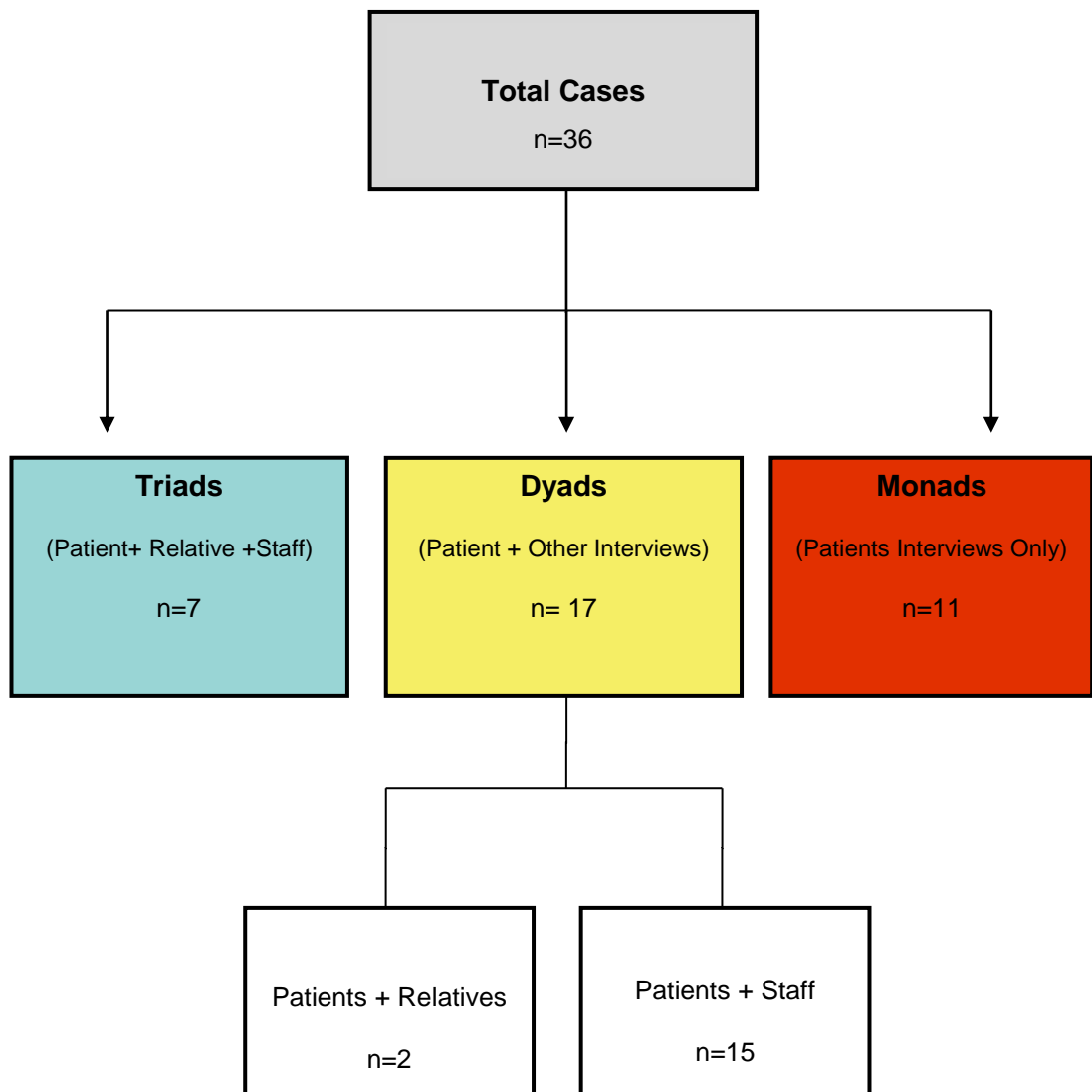
#### ***4.1.1.3: Relatives and staff to whom patients speak about their delusions and who they nominate to speak with researchers***

Out of a total 25 patients who nominated others, 16 nominated someone from their social circle and 22 nominated a member of staff to whom they said they could speak about their beliefs. Thirteen of them nominating from both social and staff contacts. Thus, 69% nominated at least one informant (see figure 4.2 for details). All relatives and staff informants were approached for interview, but seven relatives and six staff refused participation. Thus, a total of nine relatives and 16 staff were nominated and interviewed. Fourteen patients did not nominate a member of staff, but all of these agreed that a researcher might approach their primary nurse. Eight of these primary nurses refused interview, leaving six cases for whom there was no nominated staff person, but the primary nurse was interviewed, bringing the total of patients with an interviewed staff member to 22.

Seven complete triads of patient-informant interviews and seventeen dyads in which interviewed patients nominated either a relative or staff member were available. In twelve cases data were obtainable only from the patient participant, because s/he did not nominate anyone to talk with, or their nominee refused (Figure 4.3)



**Figure 4.2: Relative and staff participants**



**Figure 4.3: Summary of interview combinations available for further analysis**

#### ***4.1.2. Relative participants***

Fifteen patients each nominated one relative and one nominated two, in each case as a person to whom they spoke about their delusion and who they would be happy for the researchers to interview. Nine of these relatives refused to participate or could not be contacted using the details offered or were never able to find a convenient opportunity to talk with a researcher. That left seven patients for whom we had relative interviews, but in one case when the nominated parent was approached, the other wanted to join the interview too – so a single interview was completed, but with two people present, both of whom contributed. In another case, both parents were nominated in advance, and they were interviewed separately. This meant that eight independently acquired relative interviews were available, from seven patients. The characteristics of the relative participants are shown in table 4.1. I have created false but gender appropriate names for them, which will be used in the qualitative analysis later.

Gender of Relative (false name)	Age	Relation ship to patient	Living with patient	Contact time with patient per week	Frequency of talking about delusions with the patient in the past month
Mary	58	Sister	No	2= 6-12 hours/2 days	Frequently (most days)
Jane	75	Mother	Yes	Could not estimate	Quite often (at least once/wk)
Stephanie *	54	Mother	No	2= 6-12 hours/2 days	Frequently (most days)
Mike*	63	Father	No	2= 6-12 hours/2 days	Could not estimate
Kevin	52	Son	No	1= Up to 6 hours/one day	Frequently (most days)
Anne	43	Friend	No	3= Over 12 hours/ 3-5 days	Frequently (most days)
Sue	72	Wife	Yes	4= 5-7 days	Frequently (most days)
Maria	51	Mother	Yes	4= 5-7 days	Could not estimate
Alice	73	Mother	No	3= Over 12 hours/ 3-5 days	Could not estimate

\* Both parents of the same patient

**Table 4.1: Relatives to whom patients spoke about their delusions**



Table 4.1 shows that most of the relative participants were parents (5/8). Nine were women: four mothers, a sister, a wife and one friend. Only one relative participant was a man. As would be expected, given the nature of the relationships, the average age of the relative participants was over 60 (median = 60.5 years, range = 43-75). Two of the mothers lived with their sons and the one wife lived with her husband, but otherwise the relative participants did not live with the patients. The table also shows, however, that they all confirmed that they spoke with the patient about his/her delusion and, in just over half the cases, this was frequently – defined as at least once most days.

We were unable to collect any information about those who did not wish to participate, except for their relationship to the patient, which the patient had clearly referred to in nominating them. Three of the seven non-participant nominated relatives were women (one mother, a sister, and one wife, a daughter) and four were men (two fathers, a son and a male friend).

#### ***4.1.3 Staff participants***

Twenty-two patients each nominated one member of staff to whom they said they could talk about their delusions. Seven of the nominated staff did not wish to participate, leaving fifteen nominated staff who consented and were interviewed. Where no staff person was nominated, 14 patients agreed that their primary nurse could be approached. Accordingly, 14 primary nurses were asked to participate, but only six of them consented and were interviewed. Details of the staff are shown in table 4.2. Again, false but gender appropriate names have been created for them. Among the seven staff who were nominated and did not wish to participate I had further information on five of them; all were staff nurses, four men and one woman.

Patients	Staff name	Age	Role in relation to patient	Contact time with patient per week (hrs)	How long known patient	Last time discussed delusion with patients	Was staff member nominated ?
1	Lydia	24	Nominated staff	Up to 6 hours/one day	Staff is not sure of the long time (at least 6 months)	Last month	Y*
	Monica	43	Primary nurse+	Up to 6 hours/one day	Staff is not sure of the long time	Last week	N
2	Salma	22	Primary nurse*	Up to 6 hours/one day	Staff is not sure of the long time	Last month	N
4	Albert	30	Primary nurse*	Up to 6 hours/one day	Staff is not sure of the long time	Never	N
5	Jacob	35	Primary nurse +	Up to 6 hours/one day	1-3 years	yesterday	N (a staff member was nominated but did not consent, so two Primary nurses were interviewed)
	George	-	Primary nurse+	Up to 6 hours/one day	Staff is not sure of the long time	could not remember	N
6	Walton	39	Primary nurse +	Up to 6 hours/one day	6 m or less	Last week	N
	Dawn	26	Nominated staff	Up to 6 hours/one day	6 m or less	Last week	Y
7	Jasper	33	Nominated staff	Up to 6 hours/one day	6 m or less	Last week	Y
	Lucy	49	Primary nurse+	Up to 6 hours/one	6 m or less	Last month	N
8	Emily	21	Primary nurse (n)	6-12 hours	6 months or less	Could not remember	Y
9	Christian	35	Primary nurse*	Up to 6 hours	6 months or less	Last week	N
10	Iris	48	Primary nurse*	Up to 6 hour/one day	6 months to a year	Last month	N

12	Alton	47	Primary nurse (n)	6-12 hours	6 m or less	Could not remember	Y
13	Ruby	26	Primary nurse (n)	Up to 6 hours/one day	6 m or less	In last month	Y
14	Charles	35	Nominated staff	Up to 6 hours	1-3 years	Today	Y
	Austin	38	Primary nurse+	Up to 6 hours/one day	Over 3 years	Last week	N
15	Tyson	38	Primary nurse*	6-12 hours	Staff is not sure of the long time	Today	N
17	Peter	35	Primary nurse*	Up to 6 hours/one day	Over 3 years	Yesterday	N
20	Jeremy	33	Primary nurse (n)	Up to 6 hours/one day	6 months or less	Yesterday	Y
26	Ronald	22	Staff Nurse	Up to 6 hours	6 m-1 year	Last week	Y
27	Craig	23	Primary nurse (n)	6-12 hours	6 m-1 year	Today	Y
30	Marian	21	Staff nurse	Up to 6 hours	6 m-1 year	Last week	Y
31	Anthony	47	Primary nurse (n)	Up to 6 hours	1-3 years	Last week	Y
32	Glenn	37	Staff nurse	Up to 6 hours	1-3 years	Last month	Y
33	Lloyd	62	Staff nurse	6-12 hours	6 m-1 year	Today	Y
36	Jonathan	55	Nominated staff	5-7 days	Over 3 years	Last week	Y

\* an 'n' after the word primary nurse, this indicates that the patient nominated this person as a confidant; where there is no 'n' after the words primary nurse, the selection of this staff member was by default because the patient did not nominate anyone, but agreed that a researcher could speak to his/her primary nurse. Where there is a + after the words primary nurse, it indicate that staff was interviewed in addition to the nominated staff. In all other cases, the staff person was nominated by the patient.

Y\* = 15 staff agreed and were interviewed (7 did not consent or were unavailable for interview and are not in the table)

**Table 4.2 Staff to whom patients spoke (nominated) about their delusions**

An overview of the information in table 4.2 shows that the median age for participating staff was 35 years (range 21-62 years). The majority were men (17, 77%), and over half of them were the patients' primary nurses, whether nominated or not. Most of the staff spent about 24 hours a week with these patients. About half of the staff had known their patients for at least a year. The table also shows that all confirmed that they spoke with the patient about his/her delusions, at various times during the month prior to interview.

#### **4.1.4 General and historical characteristics of all study patients**

The median age of the 36 patients recruited was 39 years (range 18-76 years). Table 4.3 shows the remaining demographic and historical characteristics of the patients according to their ability to nominate people in whom they confided about their delusions. Ability to nominate meant that they could both nominate staff or relatives as people they could speak to about their delusions and were happy for us to interview them. Inability to nominate meant that the patients either reported that they spoke to no-one about their beliefs (5 patients) or, if they did, that they did not want us to approach the person to whom they spoke (6 patients). This decision on group allocation had to be taken because of the small sample size. I would have preferred to treat those who never spoke about their delusions separately from those who said they did but denied us access to their confidants; the rationale for combining them was that they were both in some way secretive about their beliefs while the other 25 patients appeared to be wholly open with anyone who would listen. From now on I shall refer to the 25 as those with an ability to nominate and the remaining 11 those who could not nominate (for any reason). It should be noted, however, that there were some minor differences between the two smaller groups. The five patients who said they did not like to speak about their beliefs with others

had median age of 51 years (range 35-62 years) but the six patients who spoke about their beliefs with other people but did not want to nominate any person to be interviewed had a lower median age (43, range 18-51 years). Only one of the former group had a history of violence, but half of the latter group did. All patients in both the small groups, however, came from a general psychiatric hospital and had chronic psychiatric illness (over 13 months), and the sex distribution was similar (2M/3W: 3M/3W). For completeness, the characteristics of each group are shown separately in appendix 17, here also split to reflect whether when the patients did nominate and allow a research interview of their confidant the confidants were from one group only (relatives or staff) or both.

Table 4.3 shows tests of association between patient characteristics and their ability to nominate a confidant to whom they spoke about their beliefs. Men were more likely to nominate than women (men 21/26; women 4/10; Fisher's exact test (FET) = 0.039). Only a third of the patients were working at the time of interview, with no differences between the employed and unemployed in nominating.

Among the 36 patients recruited, the largest group had never married; allowing for divorce and separation too, single status was predominant (20, 61% of the 33 for whom marital status was certainly known), there was no difference between nomination groups by marital status. It worth noting that two of the five currently married/cohabiting patients did not nominate any person to whom they spoke about their delusions.

Table 4.3 also show that nearly half of the patients had a history of violence, whether sustaining a conviction for it or not, and nearly half had a criminal history, whether this included violent offences or not. There was no difference in nomination group according to criminal or violent history when details of nominations were

considered (See appendix 17) but it was slightly but significantly more likely that those with any offending history would make some nomination than none at all.

Finally, table 4.3 shows the distribution of psychiatric diagnoses and the nature of hospital units of residence at the time of interview. More than half of the patients had a diagnosis of schizophrenia (21, 58%), the next largest group was of bipolar disorder (8, 22%) five patients had other chronic psychotic illnesses. Detailed analysis of the three nominating groups (Staff only nominated, Relative only nominated or Both Staff & Relative nominated) according to diagnosis again left diagnostic groups which were too small for analysis, as shown in appendix 17.

People with a diagnosis of schizophrenia were almost twice as likely to nominate someone (18/21, 86%) as patients with other psychoses (7/15, 47%); FET 0.025; (See table 4.3).

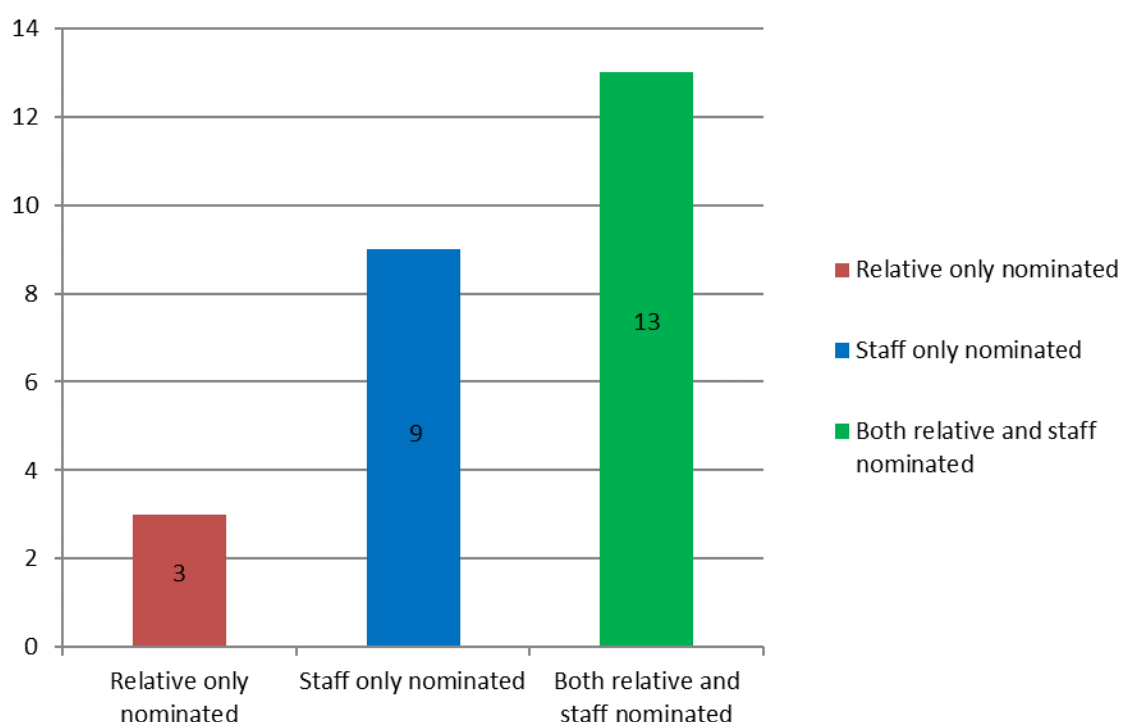
Only one patient from the forensic hospital unit recruits was unable to nominate a staff or relative informant, while nearly half of the general hospital unit patients failed to do so. This difference may have been confounded by the finding with respect to diagnosis, as a diagnosis of schizophrenia was more likely in the forensic unit (11/12) than in the general units (10/24; FET= 0.005 ). I attempted a multivariate analysis here as there might be an interrelationship between schizophrenia and being in a forensic unit, given that both are more likely to be associated with violence than other psychotic diagnoses and being in open psychiatric conditions. I therefore used multinomial logistic regression, with ability to nominate as the dependent variable and diagnosis (schizophrenia/not schizophrenia), placement (secure unit/not secure unit) and history of violence as the independent variables. The model, however, was not significant and hence not valid (Cox-Snell  $R^2$  0.565)

<b>PATIENT CHARACTERISTICS</b>	<b>No nomination n (%)</b>	<b>Any nomination (relative/ staff/both) n (%)</b>	<b>Total n (%)</b>	<b>Statistics</b>
<b>GENDER</b> M F	5 (19) 6 (60)	21 (81) 4 (40)	26 (72) 10 (28)	<b>FET=0.039</b>
<b>OCCUPATIONAL STATUS</b> Unemployed Employed	9 (41) 1 (10)	13 (59) 9 (90)	22 (69) 10 (31)	FET=0.11
<b>MARITAL STATUS</b> Single Living with partner/Married Divorced/Separated/Widowed	5 (25) 2 (40) 4 (12)	15 (75) 3 (60) 4 (12)	20 (61) 5 (15) 8 (24)	FET=0.50
<b>LIVING STATUS</b> Alone With family members/friends	7 (35) 4 (33)	13 (65) 8 (67)	20 (62.5) 12 (37.5)	FET= 1
<b>HISTORY OF VIOLENCE</b> Absent Present	5 (33) 4 (25)	10 (67) 12 (75)	15 (48) 16 (52)	FET= 0.70
<b>OFFENDING HISTORY</b> Absent Present	5 (31) 3 (21)	11 (69) 11 (79)	16 (48.5) 14 (42)	<b>FET=0.047</b>
<b>PSYCHIATRIC DIAGNOSIS</b> Schizophrenia Schizoaffective disorder Bipolar disorder Other	3 (14 ) 2 (100) 4 (50) 2 (40)	18 (86) 0 (0) 4 (50) 3 (60)	21 (58) 2 (100) 8 (22) 5 (14)	<b>FET=0.021</b>
<b>PSYCHIATRIC DIAGNOSIS</b>  Schizophrenia Other diagnoses	3 (14) 8 (53)	18 (86) 7 (47)	21 (58) 15 (42)	<b>FET=0.025</b>
<b>HOSPITAL TYPE</b> General Forensic	10 (42) 1 (8)	14 (58) 11 (92)	24 (67) 12 (33)	<b>FET= 0.043</b>
<b>TOTAL PATIENTS n (%)</b>	n=11 (31%)	n=25 (69%)	n=36 (100%)	

**Table 4.3 Summary of whether patients nominated a confidant (about delusions) or not according to demographic and illness characteristics**

## 4.2 Patients preferences for person to whom they talk about delusions

In summary, 31 (86%) of the 36 participating patients said that they talked about their most important delusion with at least one other person. 25 (81% of the talkers; 69% of the total) of these were able to specify to whom they spoke and allow us to speak with (i.e. nominate) their confidant. The largest group of those nominating were equally happy to speak to relatives or staff (13, 52 %). Where only one person was nominated, he/she was three times more likely to be a staff person (9, 29%) than a relative (3, 10%). Overall, there was a tendency towards patients being more likely to specify talking to staff (22, 88%) than relatives (16, 64%).



**Figure 4.4 Distribution of patient participant preferences of people they nominate as people to whom they speak about their delusions.**



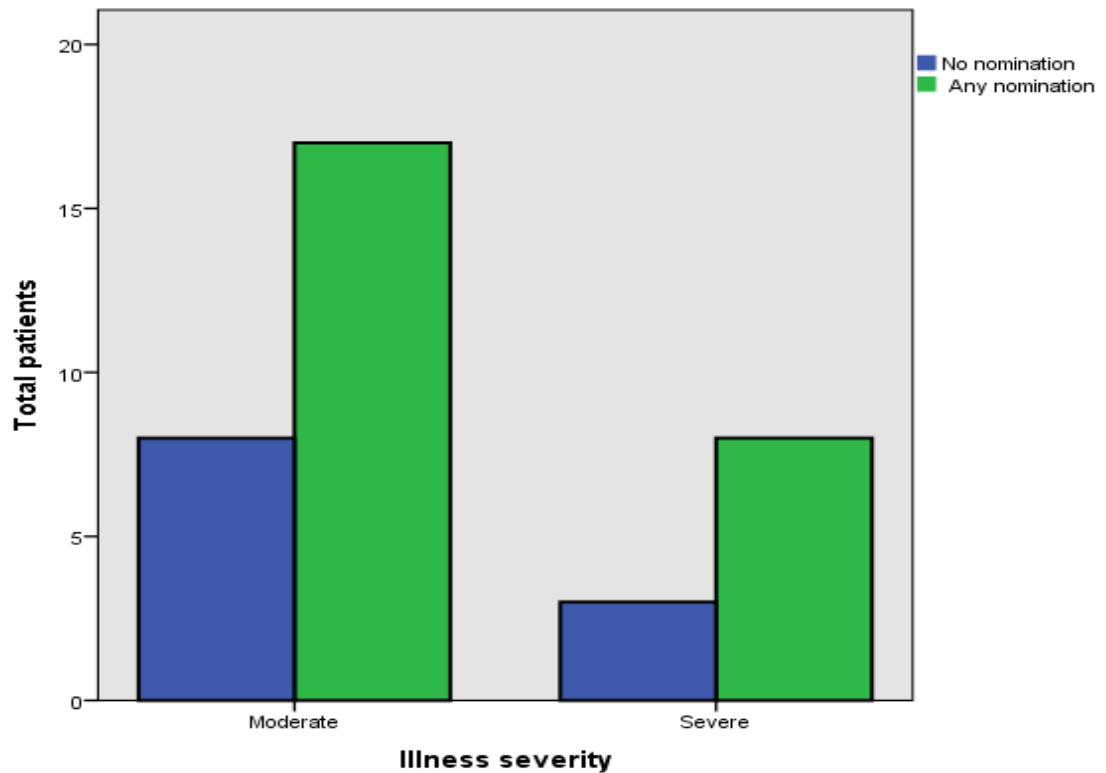
## 4.3 Variables associated with the ability to nominate a confidant

### 4.3.1 Illness severity and nomination of a confidant

At the end of the research interview schedule the researcher makes a global rating of the severity of the patient's illness according to whether it is, after all, not present, present but only to a minimal degree, moderately severe, or severe and incapacitating. All the interviewed patients had a rating of at least moderately severe. About one third of them were rated in the most severely ill group. As shown in table 4.4 and figure 4.5 severity of illness did not appear to affect nomination of people to whom they had spoken about their delusions.

ILLNESS SEVERITY	No nomination n (%)	Any nomination (SO/ Staff/Both) n (%)	Total patients in severity category n (%)	Statistics
Moderate	8 (32)	17 (68)	25 (100)	FET=1
Severe/incapacitating	3 (27)	8 (73)	11 (100)	

**Table 4.4 Overall global severity of illness (according to CPRS)**



**Figure 4.5 Overall global severity of illness (according to CPRS)**

CPRS subscales and individual items were then considered in more detail. According to the depression subscale (See Table 4.5), about a third of the patients were depressed during the month prior to interview. About one third both reported sadness and appeared to be sad. When the symptoms of depression were taken singly, none appeared to affect whether the patient nominated a confidant or not (Appendix 19).

Moreover, two thirds of the patients responded affirmatively to more than one depression symptom. Median score on the depression subscale of the CPRS was 2 (range 10). The overall depression score was 2.94. There was no association between the cut-off of five or more symptoms and ability to nominate (Table 4.5).

We established this cu-off as, to the best of our knowledge, there is no published figure in the literature. In addition, there was no association between numbers of depressive symptoms reported and ability to nominate (FET=0.31). Further details are shown in appendix 20.

<b>Depression (<math>\geq 5</math> of any symptoms)</b>	<b>No nomination n (%)</b>	<b>Any nomination (SO/ Staff/Both) n (%)</b>	<b>Total patients in the depression group n (%)</b>	<b>Statistics</b>
Absent	7 (28)	18 (72)	25 (69)	FET=0.70
Present	4 (63)	7 (64)	11 (31)	

**Table 4.5 Depression ( $\geq 5$  symptoms on the CPRS depression subscale) and ability to nominate**

#### **4.3.2 Patient reported psychotic symptom and nomination of people to whom they spoke about their delusions**

All the participant patients, by definition, had at least one delusion, and the majority had at least one class of hallucination with commenting voices being the commonest (15, 43% of patients with delusions). Other forms of hallucination were rare, with just three patients reporting visual hallucinations and just one with olfactory hallucinations.

Among the patients with delusions, the persecutory type was the most common, affecting a majority of the patients (20, 57%), then passivity delusions (11, 31%) and then grandiose delusions (10, 29%). Other delusional experiences were very infrequent; just two patients were experiencing delusional mood and another two had morbidly jealous delusions. Thought interference was the other main type of psychotic experience. Nearly half of the patients reported thought interference of some kind (17, 49%).

None of these symptoms taken singly appeared to affect whether the patient nominated a confidant or not (see table 4.6). In fact, all except two patients had more than one psychotic symptom (median=3, range=6). There was no association between numbers of psychotic symptoms reported and nomination ( $F=0.61$ ). Further details are shown in appendix 21.

<b>CPRS Psychotic symptoms</b>	<b>No nomination n (%)<sup>1</sup></b>	<b>Any nomination (relative staff/both) n (%)</b>	<b>Total patients n (%)</b>	<b>Statistic</b>
<b>Feeling controlled</b> Present Absent	4 (40) 6 (60)	7 (28) 18 (72)	11 (31) 24 (69)	FET=0.68
<b>Disrupted thoughts</b> Present <sup>2</sup> Absent	7 (70) 3 (30)	10 (40) 15 (60)	17 (49) 18 (51)	FET=0.14
<b>Ideas of persecution</b> Present Absent	8 (73) 3 (27)	12 (50) 12 (50)	20 (57) 15 (43)	FET=0.28
<b>Ideas of grandeur</b> Present Absent	2 (20) 8 (80)	8 (32) 17 (68)	10 (29) 25 (71)	FET=0.68
<b>Delusional mood</b> Present Absent	1 (10) 9 (90)	1 (4) 24 (96)	2 (6) 33 (94)	FET=0.49
<b>Ecstatic experiences</b> Present Absent	4 (40) 6 (60)	4 (16) 21 (84)	8 (23) 27 (77)	FET=0.18
<b>Morbid jealousy</b> Present Absent	0 (0) 10 (100)	2 (8) 22 (92)	2 (6) 32 (94)	FET=1
<b>Other delusions</b> Present Absent	1 (10) 9 (90)	9 (37.5) 15 (62.5)	10 (29) 24 (71)	FET=0.21
<b>Commenting voices</b> Present Absent	4 (36) 7 (64)	11 (46) 13 (54)	15 (43) 20 (57)	FET=0.72
<b>Other auditory hallucinations</b> Present Absent	3 (33) 6 (67)	7 (28) 18 (72)	10 (29) 24 (71)	FET=1
<b>Visual hallucinations</b> Present Absent	2 (18) 9 (82)	1 (4) 23 (96)	3 (9) 32 (91)	FET=0.22
<b>Other hallucinations</b> Present Absent	0 (0) 11 (100)	1 (4) 23 (96)	1 (3) 34 (97)	FET=1

<sup>1</sup> Percentages within columns

<sup>2</sup>Rated as a delusion when score scale was 2 or 3

**Table 4.6: Patient reported psychotic symptoms as rated on the CPRS and ability to nominate a confidant.**

As seen above, in table 4.6 I have performed 12 independent tests. I am aware of the risk of multiple testing. There was no statistically significant difference in symptoms between patients with an ability to nominate and those without, but had there been, I would have attempted a statistical adjustment. My preference would have been for the Bonferroni correction as it is probably the most widely used method for guarding against the risk of false positives arising through repeated testing effects.

### **4.3.3 Affective impact of the patient's most important delusion and the ability to nominate a confidant**

Table 4.7 below shows how the affect relating to the delusion which each patient had chosen as his or her most important belief related to ability to nominate any staff or relatives to whom s/he spoke about the delusions. Just over three-quarters of the 36 participant patients reported that their self-rated most important delusion made them feel anxious (28, 78%) and more than half said it made them feel frightened, angry or sad. One third (10) said that their delusion made them feel elated.

About two thirds of patients who felt frightened, angry, depressed, anxious or elated about their delusions were able to nominate at least one person whom they talk to about their delusion, so regardless of different affects associated with their delusions, patients tended to nominate rather than not. There was no significant difference in nominating according to the accompanying affect (table 4.7). There was no association between negative (terrified, angry or sad) affective impact reported and ability to nominate ( $FET=0.69$ ). Further details are shown in appendix 22.

<b>Affect accompanying delusion</b>	<b>No nomination n (%)</b>	<b>Any nomination (relative/ staff/both) n (%)</b>	<b>Total n (%)</b>	<b>Statistics</b>
<b>Frightened</b>				
Present	6 (30)	14 (70)	20	FET=1
Absent	5 (31)	11 (69)	16	
<b>Angry</b>				
Present	7 (33)	14 (67)	21	FET=0.72
Absent	4 (27)	10 (71)	14	
<b>Sad</b>				
Present	7 (32)	15 (68)	22	FET=0.1
Absent	4 (29)	10 (71)	14	
<b>Anxious</b>				
Present	8 (29)	20 (71)	28	FET=0.67
Absent	3 (38)	5 (63)	8	
<b>Elated</b>				
Present	2 (20)	8 (80)	10	FET=0.68
Absent	8 (32)	17 (68)	25	

**Table 4.7 Patient's ability to nominate someone according to the affective impact of their delusion**



#### **4.3.4 Violent acts associated with the most important delusion and the ability to nominate**

Seven of the eight patients who had recently hit someone because of their delusion also said that they spoke to others about their delusion and were able to nominate at least one person to whom they spoke about it as someone they would also be happy to be approached for interview. Equally, most of those who had been non-violent were able to nominate a confidant (17, 65%) – so there was no difference between violent and non-violent participants in ability to nominate.

Similarly, the majority of those who said they had lost their temper, felt like hitting another person or who broke things were able to nominate someone they spoke with about the belief. For completeness, statistical tests (Fisher's exact) were performed for each comparison, although numbers were very small, and these confirm that there were no statistical differences between the aggressive and non-aggressive groups in being able to nominate a confidant (see appendix 23)

#### **4.3.5 Content of delusion and ability of patients to nominate confidants**

Two thirds who had religious delusions and both of those with erotomaniac delusions, and the one with morbid jealousy nominated at least one person to talk to about their delusion, as did the majority of the patients with grandiose delusions (4/6). Most patients were not, apparently, inhibited from confiding in others about their belief when that was persecutory in content, as 12 (67%) of those in this largest single group of self-rated 'most important delusion' did so and nominated a confidant. The one patient with a hypochondriacal delusion did not talk about it to anyone else. There was no effect of content type on nomination (FET= 0.78; further details are shown in appendix 25).

#### **4.3.6 Summary of the patient characteristics, including properties of their *most important beliefs*, which affect their ability to nominate people they can talk to about that belief**

By definition, every member of the group of 36 patients who participated in this study had at least one delusion. Almost all of them (31, 86 %) said that they spoke with others about their delusions and most (22, 61%) also nominated at least one person to whom they spoke about their self-rated most important belief as someone they would be happy for the researcher to interview. A diagnosis of schizophrenia was more likely to be associated with the ability to nominate than other psychotic diagnoses, but there was no other diagnosis or delusion characteristic that was related in this way. In particular, it is worth noting that paranoid content of delusions did not usually appear to be a barrier to communicating about the belief or nominating a confidant. Aggressive behaviour, measured in different ways, did not differentiate those nominating a confidant from those not doing so, but being in a forensic hospital unit rather than a general psychiatric unit was associated with greater likelihood of nomination. Type of unit of residence may have been the explanation for the effect of diagnosis, as there was a significantly greater likelihood of a diagnosis of schizophrenia in the forensic unit. This may also have accounted for the finding that more men than women nominated; there was a higher male: female patient ratio in the forensic unit.

## **4.4 Agreement and disagreement between patient, relative and staff perceptions of the most important belief and its characteristics**

There were only seven complete triads of patient-informant interviews in which interviewed patients, a relative and staff member had all made independent observations about the belief the patient had designated as his/her most important belief, but only 12 patients for whom there were no independent observations on their beliefs. It was, therefore, possible to explore congruence and dissonance in accounts for the majority (2/3) of the patients. For the purpose of comparison between the three parties on full/partial agreements, my research colleagues and I have derived codes and created a table from the MADS answers. The table represents the three participant groups and the codes for their answers; 1 as 'yes' answer, 2 for 'no' and 9 for 'no answer'. (See appendix 26 for the preliminary coding system and appendix 27 for table details)

### **4.4.1 Patient preferences in talking with others about beliefs**

Communication about the beliefs was almost invariably by talking about them; only four patients reported writing about their beliefs, and all except one of these also spoke about them to others.

The majority (31/36) of the patients said they had told at least one person about their beliefs, and, where relative and staff accounts were available there was good agreement between the patients, relatives and staff on this point – all but one relative and one member of staff. The relative (case 26) dissonance was intriguing

as it was in the case for whom both parents were interviewed separately. The father said that his son spoke with him about his beliefs, but the mother said that he did not speak to her about them. In the other six full triads of patient, relative and staff person reporting separately, there proved to be complete agreement that the patient talked about his/her belief.

About a fifth of the patients who answered the question about who they preferred to speak to about their beliefs (7/34) expressed a clear preference for speaking about it only with staff, while four patients wanted to speak only with relatives. Just over half (19/34, 56%) said that they were happy to speak with both relatives and staff. Such preferences were not, however, invariably understood by the informant participants. Just two relatives' accounts agreed with the patients' reports that they preferred to speak to both staff and relatives, three disagreed; in two cases they thought patients were happy to speak to both when the patient had said that the preference was to speak only with a relative, and in one case the relative thought there was no such preference when there was.

Nineteen of the staff were interviewed and expressed a view on communication preferences; under half of them (9/19) reported in the same way as the patient; six agreed that the patient was comfortable talking with either relatives or staff and three that the patient's preference was to speak only with a relative. Ten staff accounts disagreed with those of the patients; seven said that the patients preferred to speak only with staff when, in fact, they had no preference, and three staff said patients were comfortable either way, when the patients had said that they only wanted to talk with staff.

When the patients were asked how often in the last month they had been speaking about their beliefs with a relative or friend, just over a third (13/35) reported never

speaking to them, 11 said that they had spoken at least once in the last month and 9 said they had spoken often in that time. Half of the available relatives (4/8) agreed with the patients' reports on the frequency of speaking about delusion with someone in their social circle (relative, friend or caregiver) during the month before interview; all four agreed that it was quite often and occurred on a regular basis. The other four, however, disagreed; two said the patient frequently spoke about his/her beliefs was frequent when these patients said they rarely spoke about them and in two cases they said that there had been no conversations about the belief although the patients had asserted that they frequently spoke about them.

When the patients were asked how regularly they were speaking about their beliefs with staff, 15 (44%) said that they had spoken at least once in the last month, 6 (17%) said they had spoken about their delusions regularly, and 11 (32%) reported never speaking to the staff; while a further two patient participants did not wish to answer this question. All these patients had been resident in the hospital throughout the month prior to interview – so all had had the opportunity to speak with staff. Reports from relatives about patient-staff interactions about the delusions and staff about relative-patient interactions showed similar patterns of difference. Only two of the available relatives (2/8) agreed with the patient's reports on the staff. Most (5) disagreed, saying that there was talk about the delusions when the patients had denied speaking about them at all; one relative simply said s/he did not know about this.

There was similar pattern for the available staff as only a few (3/18) concurred with the patients' reports; one on talking about the belief not very often, and two on talking on a regular basis. The majority of staff (15/18) disagreed with the patients' reports.

When the patients were asked how often in the last month they had been speaking about their beliefs with a relative or friend, just over a third (13/35) reported never speaking to them, 11 said that they had spoken at least once in the last month and 9 said they had spoken often in that time. Half of the available relatives (4/8) agreed with the patients' reports on the frequency of speaking about delusion with someone in their social circle (relative, friend or caregiver) during the month before interview; all four agreed that it was quite often and occurred on a regular basis. The other four, however, disagreed; in two they said the patient frequently spoke about his/her beliefs when these patients said they rarely spoke about them and in two cases they said that there had been no conversations about the belief although the patients had asserted that they frequently spoke about them. Half of the staff (10/20) agreed on the frequency with which patients were talking to relatives or friends - five on high frequency, three on speaking only sometimes and two on not speaking in the last month. The staff whose accounts differed variously said that the patients had spoken about their delusion quite often when patients had denied speaking with them (4 staff), that they had not spoken with the patients about their delusion in the past month, when the patients had said that they did (3 staff), or that they spoke sometimes when patient had denied talking about the belief at all. In two cases the staff did not answer the researcher on this question.

#### **4.4.2 Perspectives on delusion content**

##### ***4.4.2.1 The relationship between the patient's free account of his/her belief content and content elicited by more structured eliciting of delusions by content***

Examination of the congruence and dissonance of patient and observer reports on the content of the belief was, in line with the MADS, based on the patient-designated 'most important belief'. In order to make comparison between the CPRS and MADS ratings, and between the three accounts on MADS delusions, both the free narrative descriptive notes of delusion (MADS) as well as the type and frequency of delusions (CPRS) were coded (See appendix 28 and appendix 29 & 31).

As well as the MADS opening description of this, the CPRS ratings of delusion content, made after direct questions and prompts about commonly experienced delusion types, were available. Types included persecutory, passivity, grandeur, ecstasy, morbid jealousy and hypochondriacal delusions. With respect to screening for passivity delusions, for example, each patient was asked:

*'Do you ever have the sense that you are not completely in control of your own thoughts or feelings or actions? Or have you recently felt yourself to be under the control of other people or forces?'*

Any suggestion of an affirmative answer was then followed by a request to describe that experience in more detail, and the final researcher judgment on the presence or absence of a particular belief made according to this, rather than a simple yes/no answer. Over half the patients (20/36) were rated as having persecutory delusions according to the CPRS interview. Where present, these were invariably selected by the patient as his/her most important belief. By contrast, delusions of control/passivity delusions were the second most commonly noted delusions,

reported in the CPRS framework by eleven patients (11/36), but in no case did a patient describe a passivity delusion as his or her 'most important delusion', and thus passivity delusions never became a focus for the MADS interview.

#### ***4.4.2.2 Comparison of patient and observer perspectives on the most important belief***

Delusions with grandiose content were described by just six patients as their most important belief and so made the focus of the MADS interview, although endorsed by ten patients when asked during the CPRS interview. Other types of 'absurd' delusions were endorsed on the CPRS in eight cases. Eight had mystic rapture, bliss/ ecstatic happiness involving insight into religious matters (i.e. religious delusions); these were distinct from grandiose delusions, and fitted closely with the concept of religious delusions. As such, they were almost invariably chosen as the most important belief (six patients).

Two patients responded affirmatively to a question in the CPRS interview to morbid jealousy beliefs, but only one of them selected such a belief as his most important in the opening free reporting for the MADS.

In the remaining case, there was an entirely different account of the belief from each party; the patient said: *'There is a conspiracy by doctors because they are after my white blood cells. They give me clozapine, and they want to continue their dodgy experiment on me. I have been monitored for more than one race of people. There are seven thousand doctors against me who are going to release the beast next week'*. The relative said: *'He is a Messiah and has been sent to earth to save the world from evil'*. The staff person, in turn, said: *'That he has a wife who he met in his*



*dreams, she lives in America, he has a ring she bought him and believes she is coming to see him soon and they are going to be together*'. Thus, although both outsider perceptions differed in some respects, they had common ground in a grandiose quality to the content; the patient's description was not without a grandiose element (7000 doctors against me implies a sense that s/he had a sense of great personal importance), but the persecutory quality of the belief predominated.

Based on the free description of the most important belief which is collected at the beginning of the MADS interview, nearly half of the patients (17/36) described delusions with persecutory content and, where so, and where independent accounts were available, relatives and staff generally did so too. The research participant relatives invariably concurred. Staff descriptions were available in 12 cases, with nine agreeing on persecutory content. In the one triad available (case 31), there was full agreement between all parties.

Eight patients described predominantly religious delusions. The one available relative (case 26) did so too, and all five available staff accounts totally concurred. Just under a fifth of the patients (6/36) described delusions with mainly grandiose content. Where accounts for both relatives and staff (2 cases) were available there was complete agreement between all parties. Two patients described an erotomanic delusion; the one available relative agreed as did the patient's staff. Another two patients described other types of delusion: one with hypochondriacal content, the other morbid jealousy, and here relatives and staff had no clue about it. No patient, relative or staff claimed the presence of other paranormal delusions or catastrophic delusions.

#### **4.4.3 Patient, relative and staff perspectives on degree of conviction about the most important belief and about belief maintenance factors**

When the participant patients were asked how sure they were about their principal belief (33/35, 94%) said they were absolutely certain, only two had some doubts. Seven of the nine available relatives fully agreed with the patients about degree of conviction, of the other two one could not answer and one thought the patient had some doubts although he expressed absolute certainty about his belief. On this point, relatives tended to have similar perceptions to the members of staff interviewed. Most (17/21, 81%) of these staff agreed with patients on conviction about the belief. The rest (4 cases) said the patients had doubts, although the patients had expressed certainty to the researchers. In all four cases with a complete triad of raters there was complete agreement between the three parties.

In contrast to the general agreement on belief content and certainty, there was little concordance between patients, relatives and staff on external belief maintenance factors. About two thirds (24/35) of the patients reported external events which supported their beliefs, but only a third (3/9) of the available relatives and a quarter (5/21) of the interviewed staff had any perception of this. In four cases both staff and relatives agreed on the presence of external factors but disagreed with patients on what they were. For the rest, relatives and staff said that they did not think there was any external factor maintaining the patient's belief.

On the other hand, when *internal* factors, such as hallucinations and/or abnormal mood), were considered, about two-thirds (63%, 22/35) of the patients described these and over half of the available relatives (5/9) concurred with them, while staff seemed less in tune to this. Where staff accounts were available, only one third of

them (7/21) agreed with patients on this point. While this appears to suggest that relatives were more familiar with this aspect of the patients' beliefs than staff, there was relative–staff agreement in four of the six cases where both observer group accounts were available on the presence of these factors.

When the interviewers asked the patients if they had looked for any evidence or information either to confirm their view or test whether they might be mistaken, nearly half of them said yes (17/35, 49%), half the relatives (4/9), and one quarter of the staff (5/21) were aware of such behaviour, with staff, thus, again appearing less aware than the relatives. There were two triads in full agreement on looking for evidence, and four dyadic agreements between patients and relatives and another four dyadic agreements between staff and relatives.

#### **4.4.4 Patient and observer perceptions on affect relating the chosen belief**

Emotional consequences of the most important belief varied from elation to depression, anxiety, fear and/or anger. All but one patient (35/36) made some sort of statement about this; and all of those who did answer the question reported that the belief affected them emotionally in some way.

##### ***4.4.4.1 The various perceptions on negative affective impact of the most important belief***

By far the most likely direction of emotion consequent on the belief, according to the patients, was negative (n=31, 86%). Fourteen patients described the full range of negative emotions - being depressed, terrified, anxious and angry at the same time,

a further four reported three negative emotions (depressed, anxious and angry) and a further six reported two (three felt anxious and terrified, two were anxious and angry, and one said he felt depressed and anxious). Four patients described experiencing more contrasting emotions, again more-or-less simultaneously; three felt anxious but also elated, one said that he felt depressed but also elated. Another seven patients reported only one affect; five were only made elated, one only anxious and one only angry.

For the twenty patients who reported being unhappy or depressed due to their most important delusion, nine relative accounts for nine patients were available and almost all (7/9) concurred with the patient; five agreed with the patient's report that s/he had depressed mood consequent upon the delusion and two that they had not. Only one relative reported not knowing anything about the emotional impact of the belief.

By contrast, just over half (12/21) of the staff agreed with patients; eleven agreed with the patient that s/he was depressed, and one agreed with the patient on euthymic mood. In eight cases the staff disagreed with the patients, in six reporting unhappy/depressed mood when the patient did not, and in two reporting normal mood when the patient said they felt depressed.

Just over half of the patients were terrified or frightened by their delusion. Where relative accounts were available, most (7/9) agreed with the patients on the presence or absence of this experience; in five cases they had independently reported that the patient was terrified, in two cases their accounts differed. In one case the relative noted the delusion had made the patient terrified when this had been denied by the patient and in one case that it had not affected the mood when the patient said it had.

Again, staff were less likely to have recognized this negative affective impact of the beliefs. In just over half of the cases (11/21) there was agreement; in eight cases they agreed that the patient had felt terrified by his/her belief, in three they had not. Disagreement was accounted for by five reporting fear induced by the delusion when denied by patient and four saying that this was not a problem when patients had said that it was.

Over three-quarters of the patients felt anxious because of their delusion, while a quarter did not. Where relative accounts were available, they were nearly in full agreement (8/9) with patients about this; six of them concurred with the patient's report that they had experienced anxiety and two agreed that they had not; one relative did not know. Only one relative reported not knowing anything about this experience of the belief.

Here, staff agreement was high too, with fourteen of them reporting that the delusions made the patient anxious when the patient had also reported this, and two in agreement on euthymic mood; five (of 21) staff disagreed with patients; two said that they experienced anxiety when the patient had denied it and another two denied it when it was reported by patients; one simply did not know.

Nearly two-thirds of patients said that their delusion made them feel angry, while a third did not. Two thirds (6/9) of the available relative accounts agreed with patients, in four cases that the patient had been angry because of the belief, and in two that they had not, but in two cases the relatives noted the angry mood when it was denied by patients; in one case the relative did not know.

The pattern was similar for the staff as two thirds (14/21) concurred with patients, with ten agreeing on angry mood and four on normal mood, in two reporting anger

when the patient did not but in four cases of disagreement being unaware of the angry mood revealed by the patients.

#### ***4.4.4.2 The various perspectives on positive emotions attributed to the patient- designated most important belief***

On the other hand, the positive emotion (elation) consequent on belief was 14%. As for the relatives' views on the positive affect attributed to the delusion, there was congruence with patients in two thirds of the cases (6/9) for which relative interviews were available; in two case they both agreed that the delusion made the patient feel elated, in four cases that it did not, but in two cases they disagreed as the relative said the delusion had not made the patient feel elated when the patient said it had.

Among the twenty-one staff who were interviewed, just over half (12) the accounts proved to be in agreement with the patients' accounts; in two cases they agreed that the patient had been made to feel elated by his/her belief, in ten that s/he had not, but there was disagreement in nine cases; four reported elation which had not been reported by the patient, five said there was no elation when it had been reported by the patients.

#### **4.4.5 Perspectives on actions on beliefs**

##### ***4.4.5.1 Assertive, outwardly directed actions on beliefs and harmful actions***

Externally directed actions included trying to stop the belief from happening, trying to self- protect or being violent. Actions could, strictly, include communication about the belief, but I considered talking and writing to others about the belief so

fundamental to understanding anything about consonance or dissonance in accounts of the belief that I dealt with it separately (See appendix 31 for further details).

When patients were asked whether they had tried to stop their beliefs from happening, slightly less than half (16/35) said yes, nearly the same proportion (15/35) said no, and four could not answer. For the whole group of 36, accounts were available from nine of the patients' relatives; three reports were the same as those of the patients - in one case both said that the patient had tried to stop it, in two both agreed that the patient had taken no actions. Five relative accounts disagreed; in three cases the relatives reported actions when the patients had denied them, in two relatives said that the patients had done nothing in response to the belief when these patients had said that they had tried to stop it from happening, one relative had no clue what was going on.

As for the staff, (9/21), there was a similarly low level of agreement between accounts on whether the patients had acted to stop the believed events from happening. There was only one agreement on action; the other eight agreements were on inaction. Over half (12/21) of the staff accounts clearly disagreed with those of the patients; five said that the patients had been active in this way when the patients had denied it, and seven denied action when patients had reported it.

Nearly one third of the patients (13/35) said they argued with other people about their beliefs, and where relatives' reports were available for these cases (4), they invariably agreed; for the majority of patients who denied arguments, the relative reports available (4) were evenly divided on the matter. The staff position was less consistent when patients reported arguments – with agreement in only four of 9 cases for whom staff reports were available in these circumstances; like the

relatives, they were nearly equally divided on cases when patients had denied arguments, with six in agreement in reporting that the patients did not argue about their belief but six asserting that the patients did argue as a result of their delusions. Where full triads were available to report on patients arguments resulting from their beliefs, there was full agreement between parties – in three cases on arguments taking place and in one case on their absence.

Harmful actions included unsafe or violent actions associated with the illness belief such as losing temper, breaking things, hitting someone and harming self. Just over half of the patients (19/35, 54%) said they had lost their temper as a result of their principal belief while the rest did not. There was little agreement on this between the patients and the relatives, or between the patients and the staff who also gave accounts who, for the most part, had been selected by the patients as their confidants. In two cases relatives and patients had reported similarly that the patient had lost his/her temper because of the belief, and in one that s/he had not, but in three cases the relatives noted lost temper when it was denied by patients, in two that it had not happened when the patient said that it had. Only one relative did not know about this. The pattern was similar for staff, with four agreeing on temper loss and five agreeing on temper control; two reported temper loss when the patient did not, but in most dissonant cases (8/11) staff were apparently unaware of temper loss revealed by the patients.

Less than a third of patients (11/35) said that they had broken anything because of their delusion whereas more than two thirds did not. Out of eight available relatives reporting on this point, only three concurred, one on the patient having broken something and two that the patient had not done so. Only one relative said s/he didn't know. On this issue the staff appeared more likely than the relatives to give a similar response to the patient; over all, two thirds (14/21) of the staff agreed, but



most of these on the absence of such action (12/14) and just two on its occurrence. Five of the other seven staff, thought that patients had not broken or damaged any property, whereas the patients said they had, and in just two case of a staff report of breakage, the patient had denied it. Three triads were available, all with all party agreement, in one case of breakage and in the other two of no breakages.

A quarter of the patients (9/35, 26%) reported having hit or hurt someone due to their delusion. For the group as a whole, only six relatives' reports were available on this; three of them concurred with the patient's report that there had been no physical violence, but two disagreed as they thought the hitting took place while the patients had denied it; one relative did not know. None of the available staff accounts (21) reported any hitting by any patient. Thus, there was good agreement between them and the 16 patients in the subgroup with staff interviews on the absence of violence, but in five cases staff appeared unaware that patients were reporting that they had been physically violent to another person.

Nearly one third of the patients (11/35) had tried to hurt/ harm themselves because of their delusion. Among the seven relatives who had reported on this point, there was agreement by three that the patient had never tried to hurt him/herself because of the belief, but in another three cases relatives had noticed harmful actions which they thought were a result of the principal belief when the patient had not reported them.

A similar proportion of staff (13/21) reported on self-harm in the same way as the patients, thus only just over half were fully aware of the impact of the delusion – or lack of it - in this respect. Of even greater concern was that concurrence of reports was almost invariably about the absence of self-harming behaviours prompted by the delusions (11/13), while in six of the eight dissonant cases, the staff said that the

delusions prompted no self-harming behaviour when patients had reported that they had.

#### ***4.4.5.2 Withdrawal actions on beliefs***

Other ways in which patients reported that their delusions interfered with their lives was in a range of activities which they said they could no longer do because of the beliefs. These included stopping seeing their friends, no longer watching TV/ listening to radio, not eating/drinking something/anything or not going to their doctors/ visiting their hospital. Other actions, in addition, included self-protection from the belief by either avoiding certain situations or running away (See appendix 31 for further details).

More than half (57%) of the patients were no longer meeting their friends.

Among the nine relatives from whom accounts were available, four concurred with patients; two were aware that the patient was no longer meeting friends and another two that they were. In another four cases relatives disagreed; two noted that patients were not meeting friends when the patients had said that they did; another two thought that everything in this respect was as usual, but the patient had said that s/he was no longer meeting friends.

By contrast, over three quarters of the available staff accounts (17/21) were in agreement with the patients in this area, with nine of them concurring on the change – that the patient was no longer meeting his/her friends, and eight on no change. Four staff disagreed with the patients; in one case a member of staff reported it when it was denied by the patient, in three that it had not happened when the patient said that it had.

Another withdrawal action was to stop watching television or listening to the radio because of the delusion. Nearly half of the patients reported this (17/36, 47%). Again, for the whole group, nine patients' relatives' reports were available; five agreements were found; four of them concurred with the patient's report that the belief had stopped this activity and in one they both agreed it did not prevent watching TV/ listening to the radio. On the other hand, there were four disagreements; in three cases the patients has said that they had not stopped watching or listening to TV or radio, but the relatives had not thought that this was the case and in one case the discrepancy was the other way round. Moreover, in another case the relative was unaware that the patient was withdrawing in this way.

Two thirds of the staff (14) reports were in agreement with the patients' reports, in eight cases staff agreeing that the delusion had prevented watching television and in six that it had not. Most of the dissonant reports (5/7) reflected staff unawareness of the behaviour although the patient had reported it

Only eight patients reported not eating or drinking because of their delusions. For the eight relatives who believed they had adequate information on this, four accounts were in agreement, in one that that the belief had stopped the patient eating/drinking and in three that it had not, but in four cases there was disagreement. In three of these, the relatives reported the problem when the patient denied it and in one that it had not happened when the patient said it had. As for the available staff accounts, the majority (19/21) agreed with the patients, in only one that delusion had had an impact on eating and/or drinking and in eighteen cases that it had not. In the two cases of disagreement, staff said the patient was avoiding food or drink when the patient denied this.

For 20 patients, the activity was explicitly about self-protection. An example here was avoiding certain situations, running away or speaking about with other people. The other fifteen patients did not. Just over half of the available relatives (5/9) agreed with the patients; two of them concurred with the patient's report that they had tried to protect themselves; three agreed that they had not. Three relatives disagreed with patients as they denied this experience when it was reported by the patients.

There was similar pattern of agreement for the staff as over half of them (12/21) agreed with the patients; in four cases they concurred that patient had tried to protect themselves, in eight that they had not, but in three the relative noted this when denied by patients, and in six that it had not happened when the patient said that it had.

#### **4.4.6 Summary of congruence and dissonance in patient, relative and professional staff descriptions of the patient-designated most important belief and its consequences**

There was good agreement between patients, relatives and staff who participated on the fact of the patients talking about their beliefs with other people, but only about 50% agreement on frequency with which this happened. There was little agreement, on the part of relatives or staff on preferences with respect to whom the patient would speak.

In the seven cases for whom there were data from all parties, in all but one, there was complete agreement on content of the belief and the degree of patient certainty about it. Changes in affect attributed to the belief, mainly negative, were reported by almost all of the patients, and all but two of the relatives described these too. Staff were much less likely to do so. More detail about the qualities of the beliefs was rarely reported consistently between the parties. Not only was there much less congruence in reporting external belief maintenance factors, but also clearly assertive actions on the part of patients were recounted by patients and not others on the one hand and others but not the patients on the other. Numbers were too small for satisfactory statistical testing, but it seemed likely that relatives' reports were generally more similar than staff reports to those of the patient, even when the actions were self- or other-directed violence. An important caveat is that agreement between relatives and patient and staff and patient was generally good for the cases for whom all three accounts were present. The greatest dissonance between accounts was between patients and staff where no relative account was available to us.

**Chapter 5:**  
**A Model of How Patients, Their Nominated  
Relatives and Professional Staff  
Understand the Patient's Main Delusion**

## **5.1 Introduction and aims**

Given the dearth of research into communicating about delusions, but the finding that patients, staff and relatives agree that it is more usual than not that patients do talk about them, my next aim was to develop a model of the communication about a patient's most important belief.

## **5.2 Methods**

### **5.2.1 The sample**

All recruited patients, relatives and staff were eligible for the qualitative part of the study.

### **5.2.2 Source and data collection of narrative**

The narratives for the qualitative study were mainly drawn from the open narratives about each patient's most important delusion. For patients there was a single source of material, which was the response to the opening question of the MADS interview (Taylor et al. 1994). For relatives and staff there were two sources, the first was the same – the response to the opening question of the MADS, and the second any narrative specifically about delusions from five minutes of minimally structured talk about the patient in the so-called five minute speech sample. The reason for supplementing the narrative by relatives and staff was that many had given very scant material in response to the MADS question. Verbatim notes were taken during the interview about the delusions, and the narrative written up in full immediately afterwards.

The five minute speech sample (FMSS) was described in detail in chapter 2. It requires that the relative or staff member speaks on audiotape for five uninterrupted minutes about their relationship with the deluded patient, following only written card prompts placed on a table in front of them, as described earlier in chapter 3.

### **5.2.3 The interviews**

#### **5.2.3.1 Patients**

The key MADS question in the patient interview followed on immediately from the general mental state interview. The opening question was informed by what had been said in that interview in which the participant had been asked if he or she had had any concerns about being influenced by other people or forces, their thinking processes, being watched, followed or threatened, being special or suspicious. Sometimes participants had clearly focussed on one concern, sometimes introduced several. If there were clearly one main concern, the interviewer said:

In the last part of our interview you talked generally about yourself and your health, I would now like you to talk a bit more about x [the main concern]. Please talk to me about this in more detail.

If there were more than one belief, then the interviewer said:

I now would like you to talk a bit more about your beliefs – you just told me about ....., - which do you think is the most important? Which concerns you most? Please talk to me about that in more detail.



After that, if the patient talked freely, the interviewer did not interrupt. If the patient talked little, some neutral prompts were allowed, for example: 'go on', 'please tell me a bit more about that'

The following is an example of what one patient said which will illustrate more clearly how this was done.

**Interviewer:** You mentioned a concern about someone or something 'religious affecting your life '. Could you tell me something more about that?

**Patient:** Where did you get that from?

**Interviewer:** you said that when we were talking a while ago

**Patient:** I have a religious belief in life after death

**Interviewer:** don't stop – please go on ....

**Patient:** I have my own religion which is a combination of many religions. I do not believe in reincarnation, that's not it, we have all been before. There have been different times and I can prove it, there has been a time ending in 2076, I have lived until 2076, there have been a time until 2020 and also until 2014. When time ends it goes back to the beginning. In the time 2014 I was fighting in the Falklands war in 1982, where I had to perform a mercy killing. I have witnesses to this, in this 1982 however I was working in London in a newsprint office and can remember my previous time here in the Falklands war. In the time 2076, when time went back I was born in AD32 and was with one of the angels who moved the stone from the cave in which Jesus was. When I remember a traumatic event from a previous time I get ill.

### **5.2.3.2 Significant others (*Relatives and Staff*)**

For the interviews with the relatives and staff, every effort was made to collect open-ended information about the most important belief in exactly the same way. There was one major limitation in some cases on being able to do this. The interviewer for each of these parties was a different person from the patient interviewer and blind to everything that the patient had said except for the class of content of this belief. One relative and one member of staff chose a principal belief which was different from the one which the patient had rated most important; this was the only discrepancy in their account – they had reported the belief, simply not chosen it as the most important. In these cases, the interviewer told the relative or staff person that this was the case and what the patient had chosen. In these cases particularly, the narrative could be sparse and so was supplemented with any material about this belief from material in the minimally structured five minute speech sample.

The following is also an actual example of how the question ‘Please tell me about your patient’s most important belief’ produced rather peripheral information, but a section of the five minute speech sample referred more directly to the belief and so was used in the analysis.

Question about the belief: .... his friends starting um, uh, telling other people that they thought he was acting a little strange. Some examples of this included um, going to the park with his top off and sleeping on the bench. Um, he shaved all his hair off.... he’d talk about certain things which they didn’t think was particularly appropriate to anything they were talking about so they just thought he was acting strange at this particular time. Um, his parents were worried about him ....

**Extract from the five minute speech sample:** *he's uh, developed a religious theme um, he's quite preoccupied at the moment with the Devil's bible and he wants to find answers um, he's not specifically saying answers to what but he, he's just saying he needs to find answers all the time. He won't, he's ordered books on the Amazon, on Amazon and, and this has included the Devil's bible and the Book of Revelations.*

#### **5.2.4 Analyses**

Transcripts of all narratives were analysed using the grounded theory method (Glaser and Strauss, 1967; Glaser 1978). Data were coded line-by-line using a process called open coding. Key words and/or phrases that captured the essence of the data were used for the categories of different ideas that were emerging from the transcripts. My supervisor and I independently analysed the responses of nineteen patients. There was 80% agreement between us on the first level categories. Any disagreement was almost entirely accounted for by one coding the data into more first level categories than the other or choosing a slightly different label for the category where an appropriate single word or brief phrase could not be taken directly from the transcript. One example of the different words/labels I came across with my supervisor while analysing and developing these categories was from a patient who said '*The neighbours installed hearing instruments in the walls so they can read my mind or tell other neighbours about it*'. Here I suggested intrusive listening whereas my supervisor developed this to be intrusive broadcasting (and listening). We then discussed and agreed that both were present in this statement. Another example was in this patient's transcript 'I am evil doctor and empty of life because I don't respond to affection. I feel dirty I am not clean'. In this case I thought 'empty life/ anhedonia' would be more appropriate but my supervisor had chosen 'unresponsiveness'; again, we agreed both were present. We also analysed

the narrative data from the seven relatives and seven staff who had been members of the complete triads of interviewees, again applying grounded theory analytic methods.

Each new transcript was coded using the categories emergent from its predecessors, adding further evidence where it arose, and adding new categories where the earlier ones did not seem to capture a new element of the script. Text excerpts were accumulated under each category to show the range of variation within them. When no new categories were emerging the data were considered to be saturated, at which point, the sample could be regarded as complete.

These first emerging categories were not mutually exclusive, so data were then examined for similarities and differences, and compared to others, using the process of constant comparative analysis. Thus, both lower and higher order categories came from the data rather than being logically deduced or forced from previous theory. The higher order categories which emerged are shown in bold type in the left hand column of the table, and the first level categories which informed them collected under each. The scripts were re-read with these categories in mind to check that they did indeed encompass the data. Notes were kept throughout about the conceptualisations and decisions made.

The criterion for the core category was that it could best encompass all the other categories and explains the area of interest. Table 5.1 summarises this process.

**Table 5.1: Stages of grounded theory (adapted and modified from Glaser and Strauss, 1967)**

<b>Stage</b>	<b>Purpose</b>
Categories	Identifying key words or phrases
Higher order categories/concepts	Categories or concepts which emerge from similarities between first order categories
The core category	The category which best encompasses all the data
Theory	The emergent model which shows the dimensions of the core category and explains its centrality and relationship with the other categories

## 5.3 Results

### 5.3.1 Categories pertaining to patients' communication

No new categories of data emerged after 19 cases, so data appeared to be saturated at this point. Although I analysed the remaining cases, this merely confirmed saturation. The categories are shown in table 5.2.

Whether believed to be of religious or paranormal origin or from a human source, whether affecting the mind or the body, by whatever means the communication was believed to have been made and whether inducing negative or positive affect, in almost all cases it was considered to have entered and affected the person deeply. This concern was apparently resolved by the patients accepting themselves as changed, bodily. One patient, for example, said:

*my crystal pipe (penis) is not working*

Another said:

*I am Elizabeth the 3<sup>rd</sup>. People ask for my advice from all over the world.*

In perhaps the most extreme case, patient experienced that his capacity for communication had stopped altogether because so much change had occurred that the person was 'empty'

*I am evil doctor and empty of life because I don't respond to affection.*

**Table 5.2 Categories of communication about delusions according to the patients' narratives**

Higher and lower order categories	Textual data examples (verbatim)	Materials that is related to communication
<b>Miraculous communication</b>		
<b><i>Communications to patients</i></b>  <b>From God/the devil</b>  Healing Blessing  Talking to  Impregnating  Sacrificing	014: I was healed by God ...I am blessed by God; I am different from others  035: God and Satan are present in my head and are talking to me, telling me of my special mission.  008: I am pregnant because of Jesus, he has chosen me to be his child  009: I have been chosen by God ... I am the virgin Mary and I am pregnant now  013: I am a modern day Jesus Christ to save the world somehow, but it means I have to sacrifice my life	<i>Where healing and blessing are the communications</i>  <i>Where God and Satan talking to him are the communications</i>  <i>Where impregnation is the communication</i>  <i>Where impregnation is the communication</i>  <i>Where sacrificing is the communication</i>

Endowing/gifting	017: I am a superhero... God chose me for being king and gave me all sorts of talents. ...I am a professor, a physicist, a preacher, and SAS soldier	<i>Where giving talent is the communication</i>
Punishing	018: I have the power of God ...'he' send me back to hell and ruin my family	<i>Where punishment is the communication</i>
Overpowering	026: Devil was getting the better of me. I can feel the Devil (spiritually) taking over the power of my spirit. The overtaking of the world by the Devil is leading to the end of the world in 2012.	<i>Where spiritual take-over is the communication</i>
Paranormal thought insertion	027: Devil puts thoughts in mind so I hurt others; sometimes God's voice tells me not to.	<i>Where the Devil putting thoughts into his mind is the communication</i>
Bad mouthing	032: Demons are making me upset, derogatory voices by one male and one female.	<i>Where the derogatory voices form the communication</i>
<b>From famous people</b>		
Composing	020: I am married to Michael Jackson but it is not legal. He composed songs for me; he calls me you're my dark child.	<i>Where composing is the communication</i>
Advising	019: I am Elizabeth the 3rd and my father is George the 7th, people ask for my advice from all over the world	<i>Where requests for advice form the communication</i>



<p><b><i>Communications from patients</i></b></p> <p><b>Miraculous attachment</b></p> <p>Attaching</p>	<p>001: I feel I am attached towards someone called Y who I never saw or met. I believe that X (ward manager) is the same person I used to love</p>	<p><i>Where attaching is the communication</i></p>
<p><b>Overtly intrusive but human communications</b></p>		
<p><b><i>Communications to patients</i></b></p> <p><b>From (unknown)</b></p> <p>Intrusive listening</p> <p>Thought broadcasting</p> <p>Anonymous human to human thought insertion</p> <p><b>From (known)</b></p> <p>Intrusive broadcasting (and listening)</p>	<p>004: they (the embarassers) make me think everyone can hear what I am thinking of</p> <p>004: There are some people who want to embarrass me, they make me angry. They make me think everyone can hear what I am thinking of.</p> <p>033: People are talking about me.... people can input thoughts into my mind and use it to make me do bad things.</p> <p>003 they [the neighbours] installed hearing instruments in the walls so they can read my mind or tell other neighbours about it</p>	<p><i>Where others hearing his thoughts is the communication</i></p> <p><i>Where enforced thought sharing is the communication</i></p> <p><i>Where thought insertion to his mind is the communication</i></p> <p><i>Where instrumental reading of his mind is the communication</i></p>

Material insertion	022: Dr X put pink in my head and I felt petrified	<i>Where putting a substance into his mind is the communication</i>
<b><i>Communications from patients</i></b>		
Mind reading	023: I am a mind reader, I can read people's minds including drug dealer	<i>Where mind reading is the communication</i>
<b>Bodily (often sexual) communication</b>		
<b><i>Communications to patients</i></b>		
Substance extraction	007: Some people have taken my semen, and left me with no semen.	<i>Where substance extraction is the communication</i>
Being touched	022: He (neighbour) touches my body and boobs, I feel terrified.	<i>Where touching is the communication</i>
Being raped	031: I got gang-raped by Tory people.	<i>Where raping forms the communication</i>
<b><i>Communications from patients</i></b>		
Being smelly	025: I had halitosis and perhaps odours in other ways	<i>Where having bad odours to distance people is the communication</i>

Others' actions as Communications		
<p><b><i>Communications to patients</i></b></p> <p>Following</p> <p>Torturing</p> <p>Betraying</p> <p>Victimising</p> <p>Experimenting</p>	<p>021: The police are following me now, there is no offence but people around are bastards and terrible.</p> <p>030: The gypsies are following me by hiding in trees using camouflage</p> <p>01: my wife sent someone to upset me, she called the police, the police started following me</p> <p>031: I am hunted and persecuted by the secret police... they tortured me and my parents</p> <p>024: My wife is cheating on me, she is doing it with everyone, particularly the neighbour</p> <p>006: My brother stole my money ...he wants me to be crazy</p> <p>015: Some people want to do an experiment on me... the leader is Gordon Brown. They tell me 'you are a puppet, they also tell me to kill myself.</p>	<p><i>Where being followed is the communication</i></p> <p><i>Where torture is the communication</i></p> <p><i>Where betrayal is the communication</i></p> <p><i>Where the act of robbery was perceived as the communication that his brother wanted him to be crazy</i></p> <p><i>Where experimenting on is the communication</i></p>

Monitoring	010: There is a conspiracy by doctors...they are after my WB.... they want to continue their dodgy experiment on me.. I have been monitored	<i>Where monitoring is the communication</i>
Poisoning	011: Psychiatric medications are poisonous ...I am being poisoned	<i>Where poisoning is the communication</i>
Bad looking	016: Dr X (consultant) doesn't like me..he says ignore her she has P.D. He and the staff look at me as a piece of crap.	<i>Where bad looks is the communication</i>
Beating	028: X was going to attack me and he had it all planned out. Beats me up when he sees me in front of all his friends	<i>Where beating the communication</i>
Murdering	034: There is sense murder network around myself. Police murdered my daughter and imminently killed other members of my family	<i>Where perceived killing is the communication</i>
Assaulting	028: My girlfriend had an affair with a guy, guy assaulted me and since then they are chasing me in a car.	<i>Where assaulting (and following) is the communication</i>
<b><i>Communications from patients</i></b>		
Investigating	029: I know how to get rid of lying from the human race – by investing in personal social hygiene and problem solving.	<i>Where investigating is the communication</i>

<b>Evidential communications</b>		
<b><i>Communications to patients</i></b>  Bible	005: People from the royal mail want to kill me through my best friend... It is so complicated; my brother in law is killed and murdered in the bible.	<i>Where biblical record is the communication</i>
<b><i>Communications from patients</i></b>  Media	012: I won the lottery and I will live forever ... and you will see that in the press	<i>Where media evidence is the communication</i>
<b>Pathological communication deficits</b>		
<b><i>Communications from patients</i></b>  Unresponsiveness	002: I am evil doctor and empty of life because I don't respond to affection.	<i>Where inability to respond is a pathology of communication</i>
Bodily loss and change	007: My crystal pipe (penis) is not working .... when I release I become alien, my face looks different in the mirror	<i>Where body damage inhibiting usual contact with others is the pathology of communication</i>

### **5.3.2: The emergent model of patients' communication about delusions**

Nearly 40 first (lower) level categories were identified, most reflecting what the patient thought that some agent, perceived to be intrusive, was doing to him/her. Some of these experiences were reported as relatively benign, such as 'healing' or 'blessing', some neutral, such as 'talking to', and some clearly threatening, such as 'overpowering' or 'bad mouthing'. The patients experienced these phenomena as a form of communication with an external agent but the quality that linked them all was their intrusiveness. A core category or concern which I labelled 'intrusiveness' thus seemed best to encompass the experiences.

The model presented in figure 5.1 illustrates the core concern and its resolution. This resolution seemed to be pathological because any resolving movement appeared to be unidirectional, and the patients thus stuck in this pathology. The mental and bodily changes were merely congruent with the intrusive communications, occasionally putting the patient into a position of making similarly intrusive, return communications him/herself (e.g. mind-reading). The resolution was also pathological by appearing consistently to fall short of resolving the sense of intrusion; the reported communications appeared no less intrusive for the change having occurred.

The identity of the communicator tended to influence the overall quality of the resultant changes. Where a patient believed that God was the agent of communication, for example, the quality could be positive, negative or a mix of the two. For instance, one patient said:

*I was healed by God ...I am blessed by God; I am different from others',  
whereas another said 'I am a modern day Jesus Christ to save the world  
somehow, but it means I have to sacrifice my life.*

By contrast, the devil/Satan's communications invariably brought negative changes, the communications of famous people invariably brought positive ones but ordinary people had a more mixed impact, with a tendency towards the negative.

As the 'resolution' of the core concern left the patients stuck, and the communications continued and appeared to the patient to be congruous with this position, free movement along the continuum and the chances of spontaneous recovery were limited or absent. The next question is what kind of construction relatives, who the patients regarded as being privy to their delusions, placed on the situation.

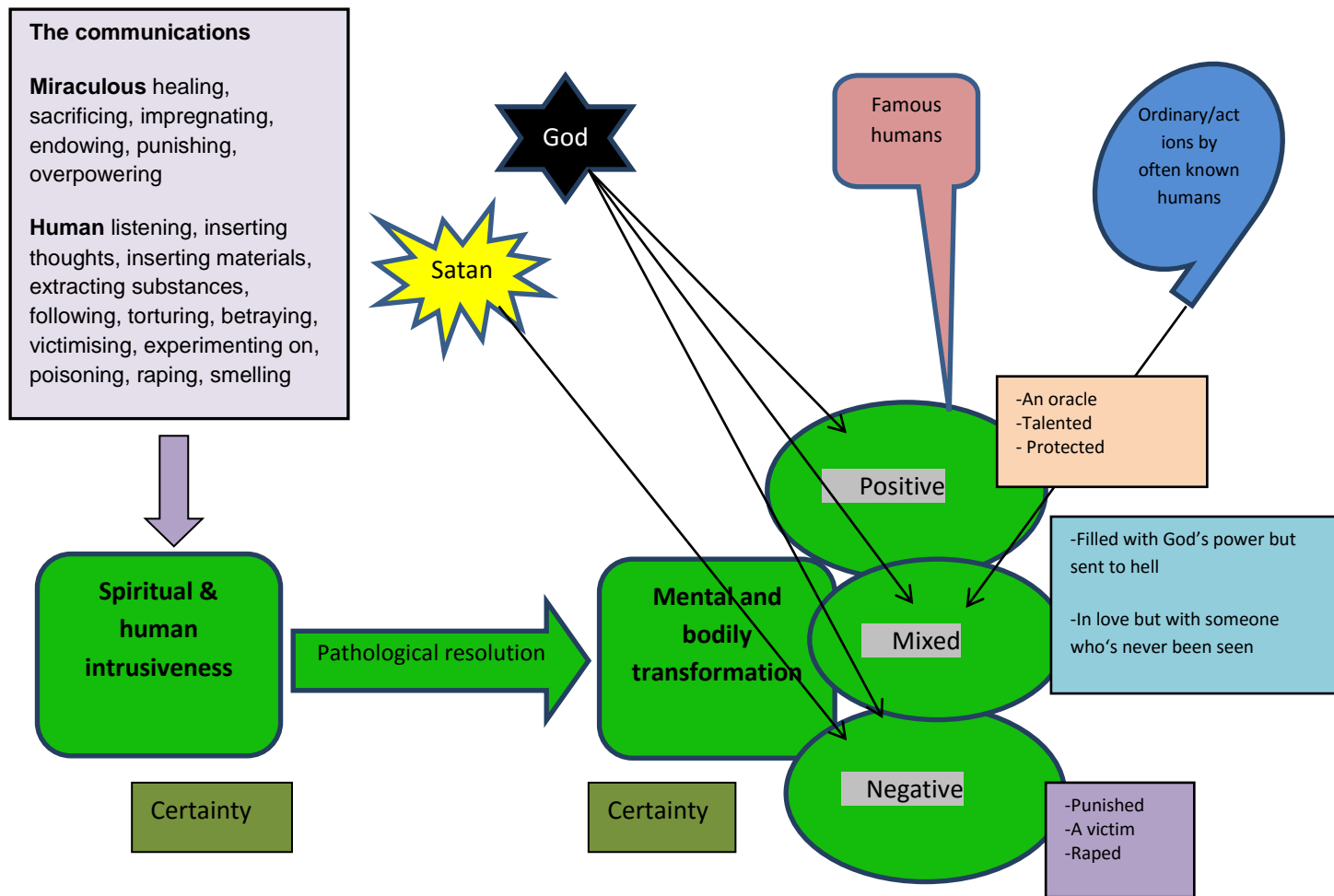


Figure 5.1 A model of the patients' experiences of communications about their delusions.



### **5.3.3 Categories of relatives' perceptions of communication with the patient**

#### ***5.3.3.1: Narratives about the 'most important' delusion***

Seven relatives' narratives were available, each in response to the question 'I understand that [name of patient] has some beliefs which may or may not be relevant to his/her illness. Please can you describe to me his/her most important belief? Although the number of the participants here was small, data saturation was reached after the sixth narrative. When my supervisor and I listed the categories and compared them, there was about 50% initial agreement. However, the agreement reached over 80% after the next re-reading and listing of the narrative transcripts. As we did during analysis of patients' narratives (described above), any discrepancies were discussed between us and were resolved. In the same way too, supplementary material was taken from the FMSS if it referred specifically to the experience of the most important delusion. No new categories were identified after the 6th interview, at which point, therefore, the data were considered saturated. Table 5.3 below shows all identified categories.

**Table 5.3: The relatives' MADS and FMSS narratives: categories touching on the patients' most important delusion**

Higher and lower order categories	Supporting data	comments
Disconnectedness		
Damaged communication	031: Paranoid, that's all we know really, it's difficult for the family not knowing.	
Puts up barriers	SO26: he's um he's put up certain barriers, um I think they are coping mechanisms on his part, and also um perhaps a protective thing um to show um, you know not to be, not to show weakness um	
Broken down communication	SO10: It isn't always easy to get to know him...you have to be a member of the family	
Angry communication	SO10: Our communication breaks down completely and um he will be so angry with us that he won't want to talk to us at all.	

Reduced/absent communication, general	SO31: when he was young he was, you wouldn't know he was in the house, he was quiet	
Reduced/absent communication, specific	SO31: I didn't know he had any paranoia, he never talked about it and I don't believe he talked about it to any of the family  SO26: lot of his self-doubts, a lot of his anxieties or fears he hasn't been able to vocalise	
<b>Connectedness</b>		
Talking	05: He talks about wife and kids from his earlier life.	
Easy	**SO28.2: quite easy to get to know	
Talking about mutual interests	So 28.1 his interests are the same as mine um <u>we talk about it</u> and he's really good to have around you	
Initiate speaking	SO28.1: he has always been open with us he's always been able to come and speak with us.	

Honest in communication	SO 28.1: He has always been honest.. when speaking with us, even when he's had problems he's been honest.	
Relative enjoyed talking	SO17: um, Well I like having his word, I like having him talk.... I like it being, being just me talking to each other.	
Voicing opinions	SO28.2: although he's shy he does like to uh voice his opinion as to what he believes in	
<b>Difficult/Stressful</b>		
Suffering	026: He believes that the way he suffers is in parallel with Jesus suffering. He said he feels like he's been crucified.	*
Psychotic	SO10: it's extremely hard to deal with somebody who is so psychotic.. he forgets that people have to get up for work um because he doesn't live in any kind of ordered world, his world is a very different world to ours	
Stressful time	SO1: She, it's very stressful spending time with her.. her behaviour is unpredictable and makes it difficult to be relaxed in her company.	

Feeling awful	SO10: I feel awful um... you know desperate, you can't, the whole thing is collapsing, we can't help him any more	
<b>Aggressive communication</b>		
Aggressive	SO17: as he gets aggressive um, yes I do find that hard. I don't want him fighting to be honest.	
Bad Tempered	SO5: he has quite a bad temper if things don't go right	
Threatening	SO10: he can be threatening, he can be argumentative. He can be psychotic and often push people away from him.	
Wearing	SO1: we try to um to have conversations with her...but that is wearing	
<b>Open/intrusive Pathological connectedness</b>		
Divine communication	017: He has had an encounter with God. God gave him light and he was saved by God's face	*

Name changing	005: He has other lives; he has other wife and children. He has names for them. He lives as a spate person with different name and life	Where the communication is his name change as a symbol of his difference
Talking constantly	SO10: He speaks constantly about his fixations and his beliefs	
Telephoning	SO1: She telephones myself and my mum three, four, five times a day sometimes in order to talk about her illness  001: She believes her husband's having an extra marital affair. She causes great embarrassment by calling people at his work...	
Continuous questioning	012: He had won a lottery, a huge amount of money. Convinced he won the lotto lottery... Always keeps on asking if lottery people have been in touch to hand over the money.	

\*These categories are report of the patient's experience of communication in relation to the delusion. The remaining categories are all about what the relative observes or experiences.

\*\* SO: Significant Other (Relative)

### 5.3.4 A model of relatives' perceptions of communication with the patient

Relatives kept referring to points which suggested that their communication with 'their patient' was impaired in some way that was commonly associated with a sense of being distanced from him or her. Sometimes this happened as the patient seemed to put up barriers through appearing stressed or hostile, sometimes the relative felt a need to back away because the frequency or intensity of the communications was overwhelming and strange. This combination of impairment and distance seemed best encapsulated by a concept of 'disconnectedness', so I considered this to be the core concern. Two quotations, although not using the actual word 'disconnectedness' seem together to capture this:

*It's extremely hard to deal with someone who is so psychotic ... his world is a very different world to ours*

or as a response to it:

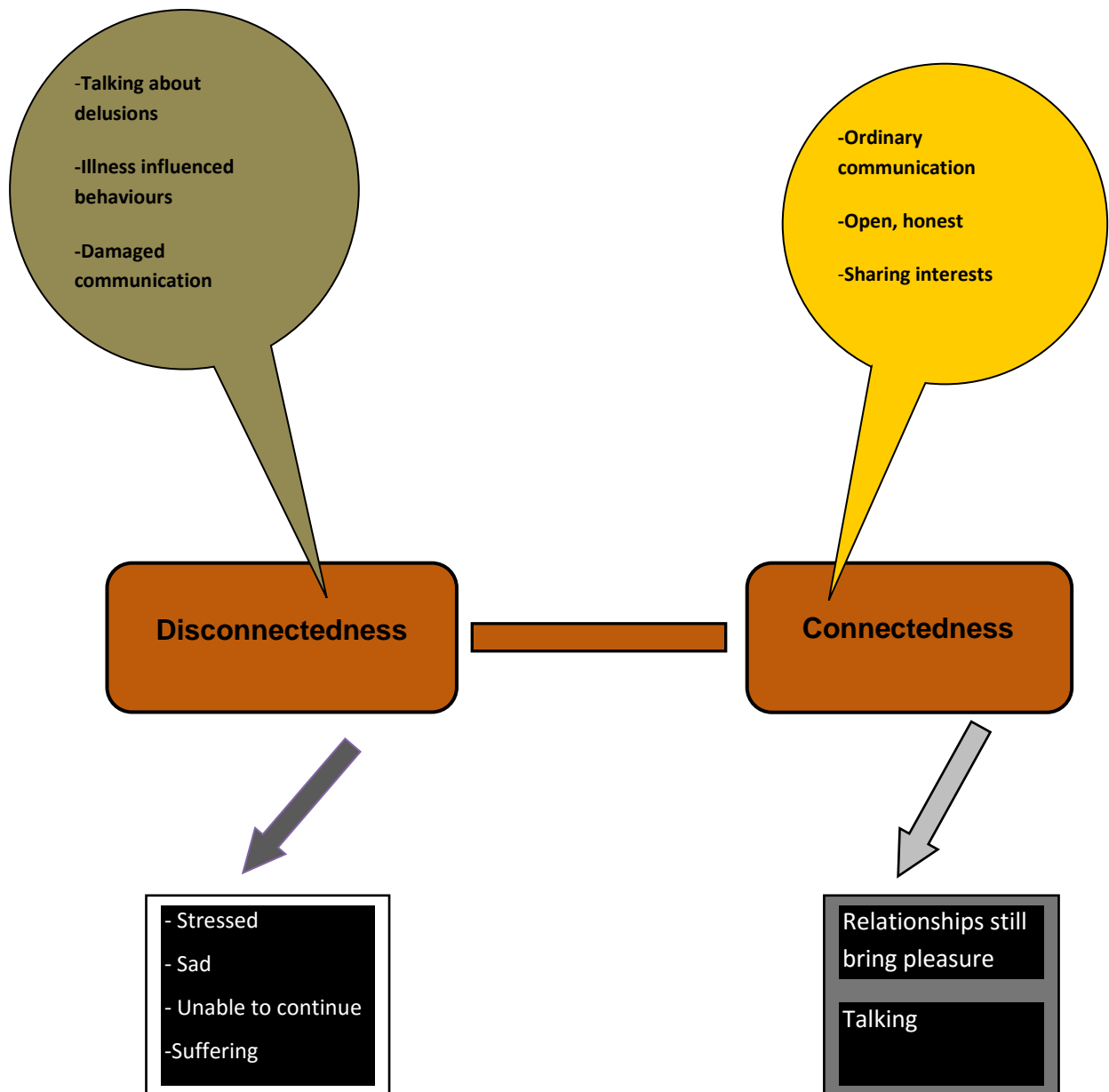
*He's put up certain barriers; um I think they are coping mechanisms ....Our communication breaks down completely and um he will be so angry with us that he won't want to talk to us at all.*

The possibility of continuum with connectedness was apparent as some relatives did feel connected, but there was little sense of movement between the poles and relatives tended to be at one extreme of the other. A sense of continued connectedness made relatives able to continue with ordinary and even pleasurable communications in spite of psychosis. One wife, for instance, said:

*'I like having his word, I like having him talk.... I like it being, being just me talking to each other'.*

Where relatives felt disconnected and that the psychosis dominated the communications. This made them feel stressed, sad, and unable to continue. The model presented in figure 5.2 illustrates this. It is much simpler than the patients' model of communications about delusions.





**Figure 5.2 A model of relatives' communication with patients**

### **5.3.5 Categories of staff perceptions of communication with the patient**

#### ***5.3.5.1: Narratives about the ‘most important’ delusion***

Similar to the process carried out with relatives, my supervisor and I analysed the staff narratives first in relation to the seven patients for whom we also had relative narratives. As with the relatives, we first rated the material from the MADS derived description of the delusion which the patient had rated as most important to him/her, and, as with the relatives, these narratives were sparse. The initial agreement between us was good (80%). No new categories were found after the 7<sup>th</sup> narrative; therefore data saturation with the 7<sup>th</sup> interview was accepted. Likewise, the five minute speech sample was used to provide supplementary data, as necessary. No new categories were identified after the 6th interview, at which point, therefore, the data were considered saturated. The categories emerging from the analysis of staff descriptions are presented in table 5.4. Any sense of communication in this context was one of things being done to the patient. Even if there was a hint that the belief might have some defensive or protective power, staff reported that belief as being in some way linked to others and acting in a damaging way towards the patient without the patient having sought that action or wanting it. Thus, for example, the patient might have special communicative powers of being able to read body language, but these only revealed that terrible things were happening because this provided the evidence of the spouse's affairs, distressing the patient. The belief might include powers to save the world, but then the incubi came and sucked his blood. The staff narratives thus far, therefore, appeared to have a core concern in common with the patients' narratives – of intrusiveness of a distorted natural world or a paranormal world of deities and demons. Unlike the relatives, the mental health staff, at this stage, were making no observations of any effect on them.

**Table 5.4: Categories from the staff narratives about the patients' most important delusion, drawn from the MADS free account and supplemented with material specific to the most important belief drawn from the FMSS**

Higher and lower order categories	Supporting data	Comments
<b>Disconnectedness</b>		
<p><b><i>Direct (explicit) barriers:</i></b></p> <p>Putting up barriers</p> <p>Changing topics</p> <p>Not listening</p> <p>Wining</p>	<p>ST001.1: She's so surrounded by her delusional beliefs that sometimes it takes a long, long time to break those barriers down and get through them.</p> <p>ST001.1: It's quite difficult to spend time with X because she doesn't stick to topic</p> <p>ST001.1: X has more interest in talking about her own personal opinions rather than listening to staff. X doesn't like to acknowledge certain things such as her delusional beliefs about staff, she refuses to, to even listen to what people have to say in terms of this.</p> <p>ST012: He believes that he had won a lottery....</p>	

<p><b><i>Indirect (Implicit) barriers:</i></b></p> <p>Preoccupation</p> <p>Disagreeing</p> <p>Lying</p> <p>Withdrawn/Asocial</p> <p>Inflexible</p> <p>Distressing family</p>	<p>026: he's quite preoccupied at the moment with the Devil's bible and he wants to find answers</p> <p>ST001.1: 'Whenever she reads her care plan she rarely agrees with them because she believes that they're all lies</p> <p>ST001.1: she believes that they're all lies and that her husband has orchestrated all of this against her'</p> <p>ST005: X: is quite socially withdrawn. He doesn't socialise or interact much with the patients or staff. He keeps himself to himself... he will often spend a day just writing to books on various football results</p> <p>ST001.1: she'll be adamant that what she knows is true and that what she be believes is correct</p> <p>031: he feels with relation to his delusional beliefs that they would cause distress to his family members actually being reminded about things that he believes have happened in the past.</p>	<p>The delusion, probably, causes the affect disturbance, but the affect rather than the delusion could directly cause this barrier</p>
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Killing	ST05: He believes that he has to kill his brother-in-law to protect his family. He believes that his brother-in-law would kill him and his mother	The direction of who is killing who appears to vary over time
Harmed	ST031: He believes that he himself and his family had been raped and tortured by secret police and political parties.	
Coerced	ST031: He is being forced by secret police to participate in crimes.	
<b><i>Indirect (Patient's affective disturbance) barriers:</i></b>		
Angry	ST010: he feels that his father had stopped his American girlfriend who he met in his dreams from coming over so he got quite angry with him and pushed him	This category shows mixed picture – some barriers but some capacity for breaking through them
Aggressive	010: I wouldn't say that he is an aggressive person, but his mental illness when it's taken over he has, with his delusional beliefs, pushed his father.	

<p><b><i>Mixed (explicit &amp; implicit) barriers</i></b></p> <p>Difficult to engage</p>	<p>031: he doesn't appear to be engaging in conversation...he does monitor what is going on and out of nowhere with no prompting he can often join into a conversation half way through with a comment</p>	
<p><b>Connectedness</b></p>		
<p><b><i>Healthy connectedness</i></b></p> <p>Media interviewing</p> <p>Pleasant</p> <p>Talking</p> <p>Easy to know</p> <p>Socialising</p>	<p>ST012 ...and a TV crew are coming to interview him about the money.</p> <p>ST031: quite pleasant and humorous</p> <p>ST001.1: She will always come back to you and let you know what's happening inside her head.</p> <p>ST010: He's quite easy to get to know; he will sit down and have a conversation</p> <p>ST012: staff appreciate socialising with x.....as it goes he's very cooperative</p>	<p>This and other categories do not relate directly to delusion but staff were able to describe capacity in spite of their delusions</p>

Compliant	ST012: X is quite compliant with staff and quite manageable.	
Amicable	ST005: he's sort of amicable	
<b><i>Pathological connectedness</i></b>		
Blood sucked	ST010:...there are female incubus sex demons and they play with him and suck his blood.	
Speaking with anyone	ST010: will talk to everybody else about his delusional beliefs	
Special communication powers/ Body language communication	ST001.1: she thinks peoples body languages are telling her that her husband is having an affair.	
Special communicative powers	ST001: She believes that her husband's having an affair with various women and staff, body language is how she knows about it.	

### 5.3.6 A model of staff perceptions of communication with the patient

As for the relatives, the core concern was of 'disconnectedness', whether directly from the delusion:

*'She's so surrounded by her delusional beliefs that sometimes it takes a long, long time to break those barriers down and get through them'*

or indirectly as in this case:

*'He feels with relation to his delusional beliefs that they would cause distress to his family members actually being reminded about things that he believes has happened in the past.'*

In addition, patient affective disturbances could have directly led to barriers to communication, for instance:

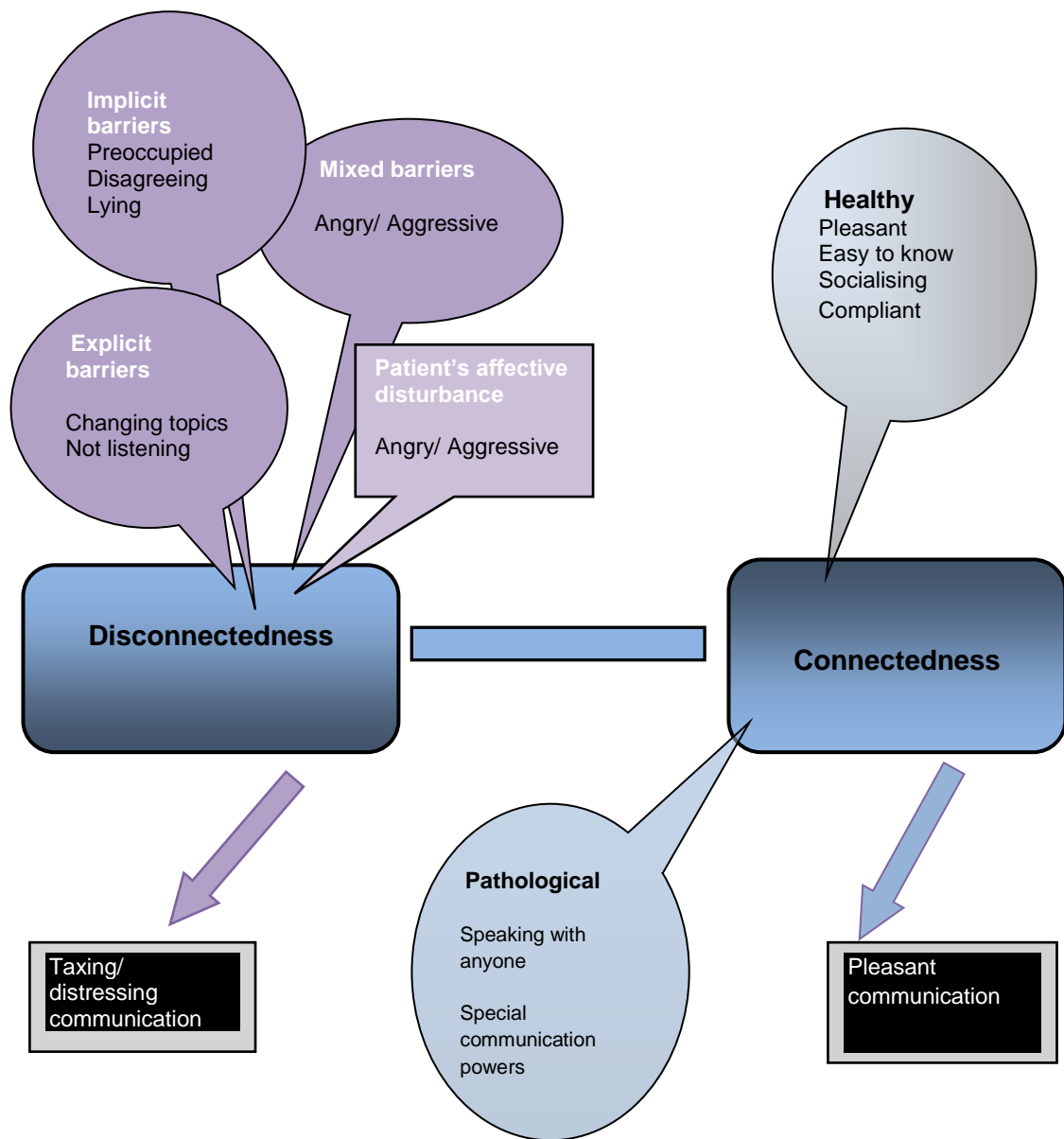
*'I wouldn't say that he is an aggressive person, but his mental illness when it's taken over he has, with his delusional beliefs, pushed his father.'*

However, there was a continuum with connectedness as some staff did report some sense of empathic relationship with the patient, but, again, there was little sense of movement between the poles and these staff tended to report experiences at one extreme or the other. A sense of continued connectedness made staff able to continue to communicate pleasantly despite the presence of psychosis as in this case:

*'She will always come back to you and let you know what's happening inside her head or this case; He's quite easy to get to know; he will sit down and have a conversation.'*

Figure 5.3 illustrates this model





**Figure 5.3 A model of staff communication with patients**

### **5.3.7 Congruence and dissonance between the three emergent models**

The core concern of the patients was of intrusiveness, with the belief itself construed as a form of communication, resolved by changing those patients mentally, physically or both and the pathway was unidirectional. The source of the believed communication affected the nature of the change. Relatives and staff were similar to each other and different from the patient in their reported perceptions of the communications focussing less on the delusion *per se* and more on how the patient talked with them about it, in no case reporting the delusion as a communication. Their core concern of 'disconnectedness' appeared, however, to have more in common than not with the patients' sense of personal change and difference. This generated a testable hypothesis that the intrusiveness of delusions results in a change which leaves all parties – the patients, the relatives and professional staff to whom they relate - feeling in some way changed and/or detached – the patient in him- or her-self and the relatives and staff in their distance from the patients.

### 5.3.8 Preliminary testing of models with reference to the literature

The models generated provide a framework for understanding how delusions are experienced by those suffering from them and those in proximity to the primary sufferer. Although I set out to find out how patients communicate about their delusions, I found that the concept of ‘communicating *about* delusions’ appears to be one for those observing the delusions rather than experiencing them at first hand. For these patients, the delusion they rated as the most important one was in itself experienced as a form of communication, which was so intrusive and relentless that it had changed them, and they had to live with that change. Few others have tried to understand the patient experience in this way, and, as far as I am aware, no one else has examined the consonance and dissonance between patient and observer experience of the patient’s most important belief in this way. Wessely et al (1993) interviewed ‘informants’ as well as patients, but these included both staff and relatives without being able to separate the two groups. Furthermore, they were selected by researchers simply as people in current contact with the patient rather than as the preferred confidants of the patients. Also, they focussed on responses to scaled items on the MADS rather than experiences of communication in relation to the belief.

Widely accepted definitions of delusions present them as experiences which are resistant to change (eg Jaspers, 1913; DSM-5 (American Psychiatric Association, 2013), so it may seem unsurprising that these patients felt so changed by them and seemed stuck in this position. Many studies (e.g. Kendler et al, 1983; Brett-Jones et al, 1987; Taylor et al, 1994), however, have shown or suggested that aspects of delusions may fluctuate, while other evidence suggests that they are not necessarily

experienced consistently throughout the whole period for which they are generally a problem for the patient (Myin-Germys et al, 2001).

Evidence on the plasticity of delusional beliefs suggests that they do often fade or disappear with the resolution of an episode of psychosis, and most clinicians would testify to this from their own experience (eg Jorgensen, 1994; Arndt et al, 1995). Longitudinal studies also suggest that the presence of delusions may vary over time and that, in certain cases they may disappear entirely, (eg Dollfus, 1995; Harrow, et al, 1994). There is, though, evidence of persistence too. Jorgensen's (1994) follow-up data on 75 patients with acute delusional psychoses, who were interviewed three times during the 8 years following discharge, showed that 43% were continuously delusional, so only just over half experienced fluctuations - 28% were intermittently delusional, and 29% had complete re-missions. The study of Myin-Germys et al (2001) was different in that they asked patients to report symptom during randomly chosen periods over six days while the patients were known to be unwell. They found that delusions only preoccupied patients for about one-third of their life experience. Their patients were described as chronically ill, but appear to have been mainly living as outpatients, so may have been less ill than the group I studied. It is perhaps noteworthy that, in this context, a quarter of the patients eligible for their study had been unable to complete the protocol, and it may be that these were the more continuously affected by their delusions.

Even when delusions persist, some data indicate that the type of delusion and/or the delusional theme are susceptible to change (Jorgensen & Jensen 1994). Given the mixed picture, even in the context of treatment, it is surprising that few efforts have been made to explore the developmental pathways of delusions and the variables which may affect these, rendering the delusions more or less life changing. The literature suggests that there are four main psycho-social cues for stability or change

- the resistance of delusions to confrontation with reality (Rokeach, 1964), self-reinforcing aspects of delusional ideation (Brockington, 1991), the potential of psychological interventions of various kinds to modify delusions *per se* (e.g. Haddock et al., 2009) and the impact of high expressed emotion in staff (e.g. Berry et al., 2010) or relatives (e.g. Kavanagh, 1992).

#### ***5.3.8.1 Resistance of delusions to confrontation with reality***

In late 1950s, Milton Rokeach, a social psychologist, carried out a study to test the strength of self-delusion. He gathered three people with schizophrenia who had a similar delusion that they were Jesus Christ, and made them live together in the same mental hospital in Michigan for two years. He hoped the patients would give up these delusions after confronting each other, but that did not happen. Instead, the three people often argued until fighting. However, they each explained away their conflicting identities. One of them believed, correctly, that the other two were patients. Another rationalized the presence of his companions by claiming that they were dead and being operated by machines. Finally, Rokeach concluded that their Jesus identities may have become more embedded after being confronted with others claiming to be Christ.

In my sample, the delusions and their perceived consequences for the patients were their reality, and this 'reality' was so intrusive that, in itself, it could be considered confrontational for the patients. This may, thus, partly explain the resistance of the delusions to change – in the mind of the patient the wider world is embracing realities which are of less personal salience than their own. The patients' natural resolution of the most important belief was to accept a profound change in themselves – in other words to accommodate to the new reality rather than to fight or confront it. This

accommodation may thus have valuable defensive value for them, presumably against the accompanying stress, even though it cannot resolve the precipitating problem. This may account for why it is so difficult, and maybe sometimes dangerous, to challenge a delusion. Thus, an aspect of the previous literature fits well with the core of my model of delusional communication in respect of the patients and, in turn, my model offers some understanding of why confronting a delusion is so ineffective

There was no evidence in this sample that staff or relatives were being confrontational, but it would have been surprising if there had been no overt challenges to the beliefs by anyone at any stage. Further, I was asking for reports of behaviour between the parties for the previous 28 days and as these patients were chronically ill, it may be that earlier confrontations about the beliefs had occurred. So, is there a way around being confrontational while not colluding with delusions? A more constructive or therapeutic approach may lie in the "hypothetical contradiction" approach of Brett-Jones et al (1987): *Asking you to think about it now, can you think of anything at all that goes against your belief that...Let me suggest something to you, something that would not fit with your belief.... If that were to be so, tell me how you think you would react, and how that would affect your belief.*

Lecompte and Pelc (1996) refer explicitly to "cognitive restructuring by correcting erroneous beliefs and distorted cognitions about the illness". Also, Gumley et al. (2003) adopt apparently robust challenges, using an approach to "identify and target beliefs and behaviours that increase risk to self or others; accelerating relapse; and develop alternative behaviours and reinforce through behaviour change". This group, however, like Lecompte and Pelc, appear to have been referring to "negative beliefs about relapse" rather than the individual's core delusional system or "most important belief". Other research by Drury and colleagues (2000) investigated the cognitive

therapy in small groups of six patients with two facilitators, in which patients were "encouraged to see how others' delusional beliefs were often supported by flimsy, inconsistent-sometimes contradictory-evidence and were asked to consider alternative explanations for them". Hogarty et al., (1997) refer to "cognitive reframing techniques".

Below, I explore more fully how the impact – or lack of it – of psychological treatments may relate to my model, but here it is worth noting a possible relationship between experienced or actual confrontation of beliefs and their growing fixity, while the opposite - creating a climate of open communication and full cooperation with the patient may help to promote his/her own understanding of his/her state and at a pace that s/he can tolerate. Almost all studies suggest that, while patients may begin to question their own beliefs at an early stage, oppositional material should not be deliberately introduced until it is clear that a therapeutic alliance had been established.

#### ***5.3.8.2 Self-reinforcing aspects of delusional ideation***

The patients in my study did report a cycle of reinforcement between belief and experienced change. The Personal construct theory (PCT) may be relevant here, although it has been applied more to thought disorder than delusions. Van den Bergh et al (1981) suggested that the thought disorders of people with schizophrenia reside in construct interrelatedness. They considered loose conceptual structure as evidence of information-processing difficulties. Construct elaboration and validation would appear to be an important factor in delusion development on the one hand and enabling people with schizophrenia to develop and maintain interpersonal skills on the other. The question is whether personal construct theory can offer the patients a

framework for understanding and modifying their beliefs and communication about them. Fuzzy logic is relevant to this theory, and representative of the way in which a large proportion of the general population manipulate uncertain concepts or those that are cognitively complex. A study by Goold and Kirchhoff (1998) assessed the feasibility of personal construct theory-oriented psychotherapy amongst male residents with chronic schizophrenia in Broadmoor Hospital, all of whom had committed violent acts and all of whom had very fixed beliefs. They showed changes in construing that occurred over a year, with an ability to consider alternative explanations of their beliefs or experiences in the treated group. A more appropriate construct system for managing personal relationships was the result of these changes.

Thinking about this work in relation to my findings, it may be that, when patients and their relatives and/or patients and clinical staff feel stuck in the psychosis, application of personal construct tools may help closer examination of the patient's difficulties and fuzzy logic based approaches enable potentially more productive conversations about the beliefs. They may allow the patient to feel safe enough to move away from self-reinforcement towards questioning his or her beliefs.

In early work with the MADS it was evident that patients sought evidence *for* their beliefs. Data from the first study, from three reports (Buchanan et al, 1993; Wessely et al, 1993; Taylor et al, 1994). The sample of the study consisted of 79 patients admitted to a general psychiatric ward, each of whom described at least one delusional belief. They studied variables including the phenomenology of the delusions, and behaviour. When the patient participants were asked whether they actively sought information to confirm or refute their belief, 22 (28%) of the 79 who answered that question said they were seeking information to confirm the belief. In



the current study, however, I found that nearly half of the patient participants (17, 47%) had looked for an evidence to confirm or refute their belief.

My model of perceived intrusiveness of a belief leading to a sense resolution into a wholly changed state, if construed as a form of self-reinforcement of the belief, is endorsed both internally from separately collected evidence in the same study of the disconnectedness and difference experienced by people to whom the patients speak about their delusions observers and externally from earlier literature. From a therapeutic perspective, this would be further evidence of the need to create a climate in which doubt can become tolerable.

#### **5.3.8.3 Other interventions to modify delusions**

Cognitive behavioural therapy (CBT) for psychosis was initially developed in part because some psychoses or psychotic symptoms were not responding to medication. Meta-analyses consistently indicate that this approach is more likely than not to be of benefit to patients, but that the effects are small to moderate.( e.g Zimmermann et al, 2005; Wykes et al, 2008). In particular, there is only limited evidence that delusions *per se* respond. Delusions became a focus for cognitive therapies following Beck's (1952) case report of improvement in a depressive delusion in the context of such work. Brett-Jones et al., (1987) and Drury et al., (2000) have taken this forward, but, in a systematic review and meta-analysis of twelve studies, Gaudiano and colleagues (2006) further questioned the clinical importance of *statistically significant* findings with respect to delusions and other psychotic symptoms. The proportion of patients showing significant and reliable scale score change in at least one psychotic symptom was significantly higher in the CBT groups than in those receiving routine or alternative treatments, but *clinically*

important changes did not distinguish the groups. Haddock et al (2009) did find that delusions significantly were improved by 10-25 sessions of cognitive behavioural therapy, but the improvement was not sustained. In my study, for the patients, the delusion was reported by them as a communication and was so intrusive that it fundamentally changed them. It may be too that this form of communication and change takes such precedence for the patient over other forms of communication that this may explain why psychological therapies which are so effective in changing some aspects of mental state have such uncertain or temporary effect on delusions. Nevertheless, the situation is not hopeless. As already indicated, forms of intervention which may open up channels of communication – like fuzzy logic approaches – may offer some hope. Ross et al (2011) offer another prospect for breakthrough. They compared 34 people with delusions and 24 comparison participants, confirming that those with delusions were more inclined to 'jump to conclusions', that is the people who had delusions required much less information than others before making a decision. A single session of training about neutral situations and the idea that it would be preferable not to reach decisions too quickly was found to have a short-term beneficial effect on such behaviour. This did not translate into any significant change in flexibility of thinking or less conviction in the delusion, but it could be argued that an absence of this further effect is hardly surprising with one session only.

The whole point of my study, however, was that I did not focus solely on the patients. My models of communication included relatives and staff. They experienced 'disconnection' and tended to feel stuck in this change and to sense little movement towards reconnecting. Psychological therapeutic attention to this form of fixity and sense of disconnection might also help. I could not find any work specific to staff in this area, and it may be that this would be an important area for development. Perhaps reflective practice or supervision would be sufficient, but there is no

evidence to this effect. There has been much more work exploring the benefits of interventions for families, but they are almost exclusively concerned with such matters as patient relapse and/or rehospitalisation (e.g. Pilling et al., 2002; Pitschel-Walz et al., 2001) or reduction in family burden (e.g. Cuijpers, 1999), important, but not tackling the question of whether by this route change in relatives' experience of disconnection – which could be protective – or change in the patient's delusion can be achieved. Garety et al (2008) is the one group to have clearly explored this and found no effect of family intervention on symptom or distress reduction in the patients, or on their duration of hospital stays; they did not even affect relapse rate.

#### ***5.3.8.4 High expressed emotion in relatives and staff***

Reflection on whether psychosocial interventions may help patients through families and others around them leads to the next consideration that the relatives' and staff concerns about disconnection raises the possibility that, far from being protective, disconnectedness may underpin alienation and, in turn, a toxic emotional climate which includes high expressed emotion.

If people feel that the patient is disconnected, then they are likely to feel disconnected themselves. In the absence of being able to make an empathic connection, it may be that staff and family members alike become more tense with the patient, and more critical of him or her. An association between this kind of emotionally tense or even hostile critical behaviour, generally known as high expressed emotion, and relapse into a psychotic state is well recognised (Brown et al, 1972). Kuipers et al (1983) found that families with high expressed emotions pay less attention to their patient-relative by listening to them less, and this may make family members genuinely feel that they have little to say about their relative's

condition and communicate with them and in turn this may disconnect the patients from them. Work with clinical staff has been particularly helpful in showing that the issue of high expressed emotion is likely to be acquired in the course of coping with the illness rather than being an inherent characteristic (Moore et al., 2002). Berry et al, (2010) reviewed the literature on expressed emotion in staff, showing some consistency in findings in this respect. Moore and Kuipers (1999) provided further evidence, that it is more useful to explore the interpersonal dynamic than to attribute attitudinal difficulties, recognising that the burden on the relatives of people with schizophrenia may be substantial. Some factors which increase the burden have been identified; the perception of the relatives on the severity of symptoms and their ability to cope with them (Barrowclough & Parle, 1997), the mood of the person with psychosis (Boye et al., 2001) and perceived hostility (Estroff et al., 1994). The patients in my study had extremely severe symptoms in the form of highly intrusive delusions, of particularly harsh impact on the relatives in these circumstances is indirectly supportive of my relatives' model for feeling disconnected and stuck in that disconnectedness. Relatives who tend to attribute blame for the disruptive qualities of the illness on the person with the illness rather than the illness itself also appear to be at higher risk for developing high expressed emotion (Chan, 2010). It would be worth taking my model to explore whether when the person with the illness has a profound sense of change which, perhaps is conveyed to the relatives and to staff, this is a major factor in a tendency to 'attribute blame' for all the disruptive misery to the person of the patient, not the illness.

It is a reality and a problem that we know almost nothing about the direction of relationships between patient and relative or staff states. When the concept of expressed emotion was first described, there was a tendency to think of it in terms of its being a deficit in the person with the problem—perhaps a dysfunctional personality trait – and that high expressed emotion might be a cause of relapse. Now, with some

opportunity to observe how relationships evolve between patients and staff, and how staff have different qualities in their relationships with different patients, it seems clearer that high expressed emotion may be a form of counter-transference. Could it be that patients with the most intrusive symptoms who feel most changed by them – and their relatives and their clinicians - are particularly vulnerable to relationship difficulties of this kind? Given that both relatives and staff in this study were split between experiencing the disconnectedness, but that this experience or its opposite were rather fixed, it seems that it is not inevitable that relationships are damaged, but this too needs further exploration.

#### ***5.3.8.5 Implications for practice and future research***

This is a small study, and this part of it designed to develop a model of understanding of communicating about delusions. It would therefore be premature to suggest that it has much implication for clinical practice, except to observe that the difficulty in recruiting relatives and staff as participants tends to add evidence to the likelihood that this is a neglected area of research because all parties tend to be avoidant of it. It may be that at the least, it indicates that staff should routinely make more efforts to engage relatives who the patients regard as people to whom they can speak about their problems and that staff themselves might ensure that their opportunities for reflective practice about such matters are safeguarded.

The models presented would be testable in further clinical research. An important first question is whether they are characteristic only of people and their contacts when the psychotic illness and the delusions are chronic, or whether this sense of intense intrusiveness and change emerges even in acute delusional states.

Longitudinal studies would be needed to clarify both the timing and sequencing of critical developments. Does the sense of profound change in person necessarily follow from the delusion, as seemed more likely in the accounts of these individuals, or could it be that the symptoms develop according to how changed the individual feels? Ultimately, the ideal is to use the model to develop novel interventions for people such as those in this cohort, who are not recovering with conventional treatments. According to my models, this would mean not only allowing, but encouraging the patient to talk about the intrusiveness of his or her most important belief within a clinical framework that feels safe for the patient and the therapist and allows the patient to question and retake real control of the script that is affecting his or her day-to-day.

## **Chapter 6:**

# **Discussion and Conclusions**

## 6.1 Summary

Delusions are common in psychotic illnesses, and yet there is very little research of any kind into ordinary, everyday communication about delusions between patients and their relatives or patients and staff. By 'ordinary' I mean the sort of conversations about beliefs that follow from a patient's spontaneous observations about them or in response to an open question rather than to highly structured questionnaires or therapies such as cognitive behaviour therapy. My systematic review of the literature confirmed the scarcity of data in this field as only three studies, which had employed very different approaches to data collection, were identified. So, my study is the first to examine how parties to an open conversation about a delusion speak about it and how similar or different they are in describing that belief in the context of semi-structured inquiry.

In a cohort of 36 people with delusion(s) admitted to a general or forensic psychiatric inpatient unit, I found that most of the patients said that they spoke to others about their delusion. In addition, I found that the majority of those who said that they spoke about their belief nominated at least one person they confided in to be interviewed. I then found, however, that half of the nominated relatives and about one third of the staff did not wish to participate in talking about this belief and their conversations with the patient about it.

A finding that interested me was that most patients reported feeling anxious, frightened or saddened by their delusion, but that the generally negative emotional impact of their self-designated most important belief did not affect their talking about it to others or their willingness to nominate these people for participation in this research. Similarly the type of content of their delusion, even when persecutory, did



not appear to have inhibited their talking about the belief. Further, having been violent, probably in the context of the belief, did not, according to them, stop them talking to others about the belief nor did it stop them from saying they would be happy for someone from the research team to contact these people.

There was good agreement between the patients, relatives and staff who did participate on the fact that some communication about the most important delusion had taken place, on the frequency of talking about it and on its content. The agreement was also good on level of conviction about the belief. Generally, relatives were more likely than staff to agree with the patient on the affective impact of the belief.

On the other hand, the staff appeared to be more consistent with patients on some harmful actions such as property damage as resulting from the belief and on some withdrawal actions, such as stopping meeting friends. Of some concern, a third of the patients reported having tried to hurt themselves as a result of the belief, but the staff had not been aware of this impact in more than half of these cases

In the absence of previous research in this area, given confirmation from the patients about the importance of talking about their delusions, I turned to qualitative methods to seek a theory of communication with respect to delusions. The core concern of the patients was 'intrusiveness' of the belief, resolved by changing themselves mentally, physically or both. The pathway appeared to be unidirectional. The belief was experienced by these patients as a communication in itself. Each patient's most important belief was complex, generally with a clearly focussed source. The source of the delusion affected the nature of the change that the patient felt as its main consequence. The core concern of both relatives and staff were of disconnectedness, which seemed like a form of endorsement of the patient's concern

about being so fundamentally changed. Relatives and staff were similar to each other and different from the patient, however, in reporting communication in a more conventional way than the patients. For them, the communication was about how the patients talked about the delusion rather than the delusion *per se*; in no case did a relative or staff person report the delusion as a form of communication. This generated a testable hypothesis that the intrusiveness of delusional communications results in a change which leaves all parties – the patients and the lay carers and professional staff to whom they relate – feeling changed and/or detached.

## **6. 2 Talking about delusions with others and ability to nominate**

A substantial majority (86%) of the patients in my sample reported speaking to at least one other person about their most important belief. Of those talking about delusions, twenty five (81%) were able to nominate. When patients were asked to nominate one or more people to whom they found it easy to talk about their delusion, the largest group nominated both staff and relatives (13, 42%), then staff only (9, 29%) and relatives only (3, 10%). Where only one person was nominated, it was more likely to be a member of staff than a relative. Thus my first hypothesis was not sustained. Although most patients talked to someone about their delusions, only about half of these (13/25) were happy to talk to anyone; most of the remainder favoured talking with staff only.

There is very little other literature on speaking about delusions with other people, but our finding is in line with one previous study of patients hospitalised for their psychosis (Buchanan et al, 1993; Taylor et al, 1994), while McCabe (2002) observed most outpatients attempting to talk with consultant psychiatrists about their beliefs.

Such findings are important because they suggest a readiness of patients to talk about their inner concerns, however pathological these may be, which may benefit them in various ways (e.g. Little et al, 2001). It is also worth noting the extent of grey literature references to carers asking questions about how to speak or respond to their relative with psychosis when they talk about a delusion or similar symptom. When I entered 'talking about delusions' into Google it generated over four million results, and 'responding to delusions' was over a million. Nearly 10% of the entries were from people seeking advice about how to respond to relatives or acquaintances with delusions and/or from others giving it.

Most individuals with chronic serious psychosis illness live with, or depend substantially on, family members (Lefley, 1987) and this close and constant contact with family members may lead to difficult relationships. Such relationships might contribute towards the likelihood of patients preferring to talk with staff rather than relatives about their beliefs. Although, as described earlier, staff as well relatives may become highly and adversely emotionally entangled with the patient, this does take time to occur, so staff are likely to be relatively protected in this respect. The term 'expressed emotion' (EE) is an essential concept here as it may affect the patient's choice about speaking with other people. EE indicates qualities in emotional climate, with high EE reflecting tension, emotional over-involvement, critical remarks and even outright hostility on the part of the family member(s). It has been found that a person who had schizophrenia is more likely to relapse when family members show high EE in relation to him/her (Brown et al., 1972), and this too may affect a patient's choice of confidant. A more multidirectional model of understanding the emergence of high expressed emotion and its consequences is now well recognized (e.g. Kavanagh, 1992), based on the stress and coping model of Lazarus and Folkman (1984). Hence, the patients' choice could have been affected by this climate.

My second hypothesis was not sustained. I found no relationship between affective impact of the delusion and ability to nominate a confidant or between having a history of violence and ability to nominate, and the sample was adequately distributed to be able to test for this 31, 86 % describing affective impact of their belief; 16, 52% with a history of violence). Indeed, no particular feature of mental state presentation, including global seriousness of illness or delusion content appeared to affect a patient's capacity to nominate a confidant.

### **6.3 Willingness of nominees to speak about delusion**

An unexpected and interesting finding was the difficulty in getting people nominated by the patients to speak about their delusions to do so. Only a few of those people showed willingness and/or ability to speak with the researchers about patients' beliefs. Only about half of the relatives and about two thirds of the staff nominated were willing to talk to a researcher about this. Unfortunately, if nominees refused to speak to one of the researchers that meant that I had no further information at all about the reason for this. It may be that this simply indicated that each of these people was too busy to give even an hour of his or her time to trying to further understanding of the problems of his/her relative or patient, but it may suggest a more fundamental problem— that people who are not the primary sufferers are uncomfortable about speaking about exchanges about such strange experiences as delusions. McCabe and colleagues (2002) observed that when patients wanted to initiate conversation about their psychotic symptoms in consultations with psychiatrists, the clinicians hesitated, responded with a question rather than with an answer, and smiled, joked or started a conversation with the relative or carer if

present rather than engage with patients' concerns about their psychotic symptoms. It is possible that reluctance to engage in conversation with the patient about delusions and reluctance to talk to others about the delusions have similar roots.

One explanation of this is that people in whom patients confide about their beliefs are uncertain how to answer and, perhaps particularly staff, are therefore embarrassed to report the exchanges. Langlands et al. (2008) consulted 45 'consumers', 60 carers and 52 clinicians from different parts of the world about essential preliminaries for assisting people with psychosis. They sought consensus through the Delphi method. Among the nine categories of unmet needs which were endorsed by the majority of the participants were the items: 'how to deal with delusions and hallucinations' and 'how to deal with communication difficulties'.

Another possible explanation for reluctance on the part of lay or professional people to talk with or about their relative or patient with delusions may lie in clinical belief, experience or both. The concept of fixity as an essential criterion of a delusional belief has long been embedded in both definitions of delusion (e.g. Jaspers, 1913) and of classification of psychotic illnesses, especially schizophrenia (DSM-IV; *Diagnostic and Statistical Manual of Mental Disorder* (American Psychiatric Association, 1994); ICD-10; International Statistical Classification of Diseases (World Health Organisation, 1994), so, despite the development of cognitive therapies towards changing beliefs (e.g. Beck, 1952; Brett-Jones et al., 1987; Drury et al., 2000), most clinicians in everyday practice may assume there is little or no point responding. Cognitive-behaviour therapy (CBT) for schizophrenia often purports to tackle symptoms of the psychosis, but few reported studies have, in practice, done this; they are much more likely to focus on illness behaviours (Taylor, 2006). A study by Wykes and colleagues (2008) tried to resolve any discrepancies between individual and review study findings using a rigorous system of six separate meta-

analyses on data extracted from 33 studies identified. They found an overall advantage for CBT on positive symptoms, negative symptoms, functioning and mood, however when only blinded studies were considered the effect was small. Efforts to modify delusions specifically were continued and another recent study by Rose et al. (2011) offered an understanding of a way forward. They compared 34 people with delusions and 24 comparison participants, confirming that those with delusions were more inclined to 'jump to conclusions', here measured by the amount of information they requested before making a decision. A single session of training about neutral situations and the idea that it would be preferable not to reach decisions too quickly was found to have a short-term beneficial effect on such behaviour. This, however, did not lead to any significant change in flexibility of thinking or less conviction in the delusion. Thus, there is little in the wider literature to encourage optimism about changing delusions by responding to them conversationally.

In respect of psychotic beliefs specifically, it has been shown that, while the delusions of some patients are unaffected by hypothetical challenge, in some cases such challenge may actually intensify and develop the belief (Buchanan et al, 1993). I know of no material on whether showing interest in delusions, or appearing to endorse them makes any difference to their progress, but this very uncertainty may further contribute to the possibility that relatives or clinicians prefer not to talk about their exchanges with a patient about his or her delusions.

Another possible explanation of the apparent reluctance of observers to talk about their interactions with a person about their delusions is that either or both of these parties become too distressed by the conversations and/or they experience change in their relationship with that patient. Several researchers have highlighted the vulnerabilities of family and professional carers alike who, in long term relationships

with a psychosis sufferer, may become highly emotional and critical in the relationships with their patient with psychosis. Work with clinical staff has been particularly helpful in showing that the problem of what is called high expressed emotion (EE) is likely to be *acquired* in the course of coping with the illness, rather than innate (Moore & Kuipers, 1999; Moore et al., 2002), but this is unlikely to stop people feeling uncomfortable about the quality of their relationships and how they talk with patients about their delusions. This may be particularly true among staff. Then, too, when people with psychosis become violent, it is relatives or friends who are most vulnerable to it, often in its severest form (Estroff, et al., 1998; Johnston and Taylor, 2004). Such experience, or a sense of being under threat, may further account for why relatives avoided talking with us about their family member with delusions. A high proportion (52%) of the sample had been violent.

On the other hand, it could be that a confidant, particularly a relative, avoided talking with the researchers because they were on a spectrum of similar difficulties. There is a continuum of severity of paranoia in the general population, with persecutory delusions only at the extreme end (Van & Verdoux, 2003). In their pilot studies, Freeman and colleagues (2002) showed that paranoid thinking about virtual reality characters can occur in students, and in people at high risk of developing psychosis (Valmaggia et al., 2007). Moreover, Freeman et al., (2008) demonstrated that individuals in the general population experience unfounded paranoid thoughts. They found over 40% of their general population sample had paranoid thoughts. These figures were consistent with other epidemiological research that indicated paranoid thinking occurs regularly in 15-20% of the general population (e.g. Freeman et al., 2005)

One particularly relevant study found that families with high expressed emotions pay less attention to their patient-relative by listening to them less (Kuipers et al,1983),

and this may make family members genuinely feel that they have little to say about their relative's condition. It is worth mentioning here that many families do not have the skills to listen or talk to their patients with psychosis compared to clinicians such as staff. Rose and colleagues (2006) found that nearly eighty percent of relatives caring for patients with different psychotic disorders were concerned that they did not know how best to talk to their ill relative. However, there is no doubt that some family members do have good abilities to communicate with their loved ones – and that was reflected in some of the narrative material in my study.

The burden of care on the families of people with schizophrenia and other psychotic illnesses may be substantial. Factors which increase the burden include the perception on the part of the relatives of the severity of symptoms and their ability to cope with them (e.g. Barrowclough & Parle, 1997), the mood of the person with psychosis (Boye et al., 2001) and perceived hostility (Estroff et al., 1994; Swanson et al., 1997). These factors may distance the family members from the patients, and limit their interest in responding to questions about their relative.

## **6.4 Congruence and dissonance between the parties in reports of the nature of the delusion**

In this study there were seven complete patient-informant triads in which interviewed patients, a relative and staff member had all made their independent observations about the patient's delusion. It was, however, possible to explore congruence and dissonance in accounts for the majority of the patients as only one third of them was without any observer account. I found that there was good general agreement on content of the belief and degree of certainty about it, but less agreement or even



disagreement on other characteristics. Hence, the third hypothesis was sustained as it suggested that agreements between the three reporting parties will be good only on some characteristics of reported delusions, while less agreement or even disagreement on other aspects such as negative emotions attributed to the beliefs, and violent action on the beliefs, whether to self or others.

I found good congruence on the description of content of delusion between the three parties. It was not surprising to find that staff were able to record the content of the patients beliefs as most of their training focuses on recording content of beliefs. In part the evidence for this lies in the classification manuals, which either hint at or describe content of delusions, and in part from the standard range of rating scales such as the Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987), The Comprehensive Psychopathology Rating Scale (CPRS; Asberg et al., 1978), Brief Psychiatric Rating Scale (BPRS; Overall & Gorham, 1962) and the Schedules for Clinical Assessment in Neuropsychiatry (SCAN; Wing et al., 1990) all of which require some recording of content of beliefs. Thus, staff practice gets shaped and, indeed, this may also explain why they are less good at reporting other characteristics of beliefs– the standard classification systems do not encourage it and few assessment tools offer the option.

#### **6.4.1 Similarities and differences in perception of affective impact of the most important delusion**

Most patients reported that their most important belief distressed them in some way – depressed, terrified, anxious and/or angry. I also found that almost all of the relative observations on the emotional impact of the belief concurred with this. It was striking

that, except in relation to anxiety, the staff observations were more likely than not to take a discordant perspective. Why should this be?

First of all, it is important to mention that there is a difference between measuring depression or anxiety disorders and measuring emotions directly attributable to delusions. Depression and anxiety disorders are among the most common diagnoses and there are several scales for the purpose of measuring them directly such as the Beck Depression Inventory (BDI), the Beck Anxiety Inventory (BAI), the Hospital Anxiety and Depression Scale (HADS), and the Depression Anxiety Stress Scales (DASS). However, The Maudsley Assessment of Delusions Schedule (MADS: Taylor et al., 1994) is unique in attempting the measurement of emotions directly associated with delusion(s). It generates scores on nine dimensions including negative affective impact. It addresses whether the delusional belief makes the people suffering from them feel depressed, anxious, frightened or angry.

Most of these patients had chronic psychotic illnesses and have been staying in hospital for a long time. To the best of our knowledge, however, their relatives were regularly visiting them. This relative-patient proximity may explain why the relatives showed comparable views to that of patients on affective impact. Proximity creates opportunities for conversation about delusions and hence better understanding. In addition, they may have spent more time than staff with the patients during the time of interviews. It was, perhaps, a limitation of this study that we did not measure this.

On the other hand, we were surprised in this study to find that staff were relatively less efficient at identifying delusion-related negative emotions. It could be, however, understandable that they missed some emotions such as feeling terrified/frightened by their delusion as this term perhaps doesn't sound like such a psychiatric term, and there are no 'fright/fear scales' in the same way as there are depression scales and anxiety scales to alert staff to these subtleties. They were no better, however, in

reporting other negative emotions consequent upon the beliefs. One explanation may be that depression may be difficult to distinguish from the feelings of anhedonia and inertia of schizophrenia, and so may be difficult to distinguish in people with schizophrenia. The fact remains, however, that we were not asking about depression or unhappiness generally, but rather emotions directly attributable to the beliefs.

Staff working in psychiatric services providing long-term support, like relatives, could have had frequent contact with patients. The staff in the current study did so as most of them spent about 24 hours a week with these patients. One other study (Omerov et al., 2004) has attempted to compare the patients' observations with those of their clinical staff on the same incidents and found that staff identified less than one half of the factors that patients reported as provocative to them. This is a consistent finding to the current study as some staff did miss important events. Another small, qualitative study with the same interest in staff-patient congruence in observations showed that staff were unable to see the world through patients' eyes and, thus, reported patient experiences differently (Secker, et al., 2004). They described the main themes to emerge from 15 staff accounts of 11 incidents on one acute admission unit located in a psychiatric hospital in south London. The data was collected over period of 5 months and 26 incidents were reported. A striking theme reflected throughout the interview data was the lack of staff engagement with clients, and particularly an inability to look at the world through clients' eyes in interpreting their behaviour. The poor therapeutic alliance or low levels of engagement or empathy may be an explanation for the dissonances but this, in turn may be related to emergent high EE, with low levels of engagement a form of defence against the terrible feelings experienced in a psychotic transference. This may emphasise the importance of closer supervision of the patient, closer contact with the patient and his/her family with improved staff communication with others and better staff training.

#### **6.4.2 Recognition of harmful behaviours towards others and self**

A quarter of the patients reported having hit or hurt someone, and nearly one third said they had tried to hurt themselves because of their delusion. Although half of the participants' relatives were not congruent with patients' reports the finding of greater concern was that one third of the staff had not apparently considered the impact of the delusion in hitting other people. Similarly, half of the staff were unaware of patient reported self-harming behaviours. How could staff not know about such risky behaviour consequent upon a delusion?

One possible explanation is that staff knew about the behaviours, but did not attribute them to the delusion. None of the staff, however, responded to the interviewers by saying that they were aware that the patient had hit or hurt someone or self-harmed but just didn't think it had anything to do with the delusion. It may, however, be a limitation of the study that we did not press the staff to establish this.

Another possible explanation could be the emotions that could develop between staff and patients over time. The qualities as I found have involved tension and critical remarks which in turn detached the staff from patient and limit their knowledge about the patient. This was consistent with other research as Moore and Kuipers (1999) found that not only may such distressing emotions be apparent in certain family relationships but also in particular staff–patient relationships.

A third explanation may lie in the fact that there are some difficulties in the nature of dialogue between patients and their clinicians (e.g. McCabe et al., 2002) which may contribute directly to violent acts. A recent study compared staff and patient

experiences of the same violent incidents in a hospital in Sweden, where staff were able to identify fewer than 50% of the provocations, that the patients reported experiencing (Omerov et al. 2004). I have already made reference to the Secker et al. (2004) study. They considered the most striking theme to be lack of staff engagement with the patients, and a particular inability to look at the world through the eyes of the patients. However, the study involved people with different mental disorders and not only those who have psychosis. Also, only one acute admissions unit was approached. Therefore, the generalizability of the results is open to question. Furthermore, Bowers et al., (2006) tested the relationship between specific nurse training in prevention and management of violence in the inpatient setting. The results, however, were rather discouraging. This suggests that more attention may be needed in the support and supervision of clinical staff, perhaps particularly general mental health service staff, and that notwithstanding the widespread advice to conduct risk assessments, important risks are being missed.

## **6.5 A testable model of understanding communication about delusions**

In my qualitative study, I found that the intrusiveness of delusional communication was the core concern of the patients, which they resolved pathologically by accepting a sense of change in their person, which was then fixed. Much of the psychiatric literature presents delusions as deeply held and resistant to change. Both Jasper's definition that beliefs with impossible content, which are held with extraordinary conviction and maintained imperviously to other experiences and compelling counter arguments (Jaspers, 1913) and DSM-5 (American Psychiatric Association, 2013) which repeats that approach in defining a delusion as "A false belief that is firmly

sustained despite what almost everyone else believes and despite what constitutes incontrovertible and obvious proof or evidence to the contrary" emphasise that delusions are fixed.

Since Beck's (1952) account of change in a delusion during psychotherapy, however, there has been growing acceptance of an alternative position - that aspects of delusions may fluctuate and scales have been developed accordingly to measure this (e.g. Hole et al, 1979; Kendler et al, 1983; Shapiro, 1961; Strauss 1969; Brett-Jones et al, 1987; Taylor et al, 1994; Peters et al, 1999). Delusions may fluctuate in another sense too – they are not necessarily experienced consistently throughout the whole period for which they are generally a problem. One study found that people with schizophrenia were preoccupied with delusion on average for only about a third of their time (Myin-Germeys et al., 2001). None of this fluctuation was apparent in this sample. This may reflect the chronicity, severity or both of the illnesses of people who, these days, are hospitalised for their condition, but improved understanding of how changed these people feel might be an important therapeutic step for them. Relatives and staff also appeared to be 'fixed', and so patients and their lay and professional carers are perhaps trapped in a vicious cycle of pathology. Relatives and staff experienced 'disconnection' as their core concern and tended to feel stuck in this change and to sense little movement towards reconnecting.

What evidence is there that this psychological understanding might help, perhaps by leading towards more therapeutic attention to this fixity and sense of disconnection? Most therapies that are founded in use of communication as a therapeutic tool have been shown to have mixed results. Evaluation of the cognitive behaviour therapies (CBT), for example, indicates that related change *in the psychotic symptoms* occur only for those who are acutely ill. A systematic review of CBT for symptom change in schizophrenia, schizoaffective and delusional psychoses was carried out by

Zimmerman and colleagues (2005). Fifteen trials were included (but not all were RCTs) in which 515 people had had CBT and 486 were in comparison groups. Meta-analysis of 14 trials discovered an advantage for CBT in reducing symptoms, with a higher effect size in acute cases compared to chronic cases. However, Improvement scores were generally agreed on the overall ratings for 'positive psychotic symptoms'. Thus, it was not possible to say which symptoms were most affected.

Considerable attention has focused on the way in which people with schizophrenia think. Personal construct theory (PCT) has generated research into thought disorder, often with divergent findings and interpretations. Loose construing is commonly taken to indicate thought disorder. Van den Bergh et al (1981) have hypothesised that thought disorders of people with schizophrenia reside solely in construct interrelatedness, seeing loose conceptual structure as evidence of information-processing difficulties. Loose construing encourages the generation of new ideas, and tight construing is necessary to test their validity in obtaining dependable prediction. Selective, or incomplete, construing may be ways whereby people with schizophrenia avoid invalidation of their beliefs or other symptoms (Van den Bergh et al., 1985). Thought disorder arises from the need to preserve the existing construct system. It derives from factors embedded within the system, rather than external events (Carroll, 1983). Times of greatest chaos have been found to coincide with periods of high emotional distress (Livesay, 1980). Unfortunately, very little recent work on thought disorder has appeared since these pioneering papers. Construct elaboration and validation appears an important factor in enabling people with schizophrenia to develop and maintain interpersonal skills.

In our study the communication between three parties was associated with intensity and disconnection, the question is whether personal construct theory can offer the patients a framework for understanding and modifying their communication. Fuzzy

logic is relevant to this theory, and representative of the way in which a large proportion of the population manipulate uncertain concepts or those that are cognitively complex. Goold and Kirchhoff (1998) carried out a pilot study investigating the feasibility of personal construct theory (PCP)-oriented psychotherapy amongst male residents with chronic schizophrenia in Broadmoor Hospital, all of whom had committed violent acts and all of whom had very fixed beliefs. They matched them with another group, rated using the same instruments, but who did not receive psychotherapy. They were able to demonstrate changes in construing that occurred over a year, with an ability to consider alternative explanations of their beliefs or experiences in the treated group. These changes included elaboration accompanied by changes in mood, and the formation of a more appropriate construct system for managing personal relationships.

Their study offers some support for the view that validating fuzzier construing may be associated with enabling people with schizophrenia to question beliefs safely and tolerate higher levels of emotion within a social context and be able to better communicate with other people. The experience of becoming 'fuzzier', of risking areas of grey, rather than clinging to a predominantly black-and-white world, proved fruitful. The close and complex associations between fuzzy construing, elaboration, validation and looseness calls for further examination. It is through such elaboration and re-construing that new ways may be discovered of delivering therapy, and offering hope, to people with schizophrenia and those around them.

The literature of the 1960s and even 1970s was rather hostile to families. Parents of people with schizophrenia were stigmatised as having caused the illness. No one wants to believe that they could have caused, even inadvertently, such terrible suffering in someone they love. This was consistent too with the label of 'schizophrenogenic parent', particularly applied to a stereotypical mother figure,



described as cold, rejecting, emotionally disturbed, perfectionist, domineering, and lacking in sensitivity, or sometimes, overprotective, encouraging dependence, and both rigidly moral and seductive (Fromm-Reichmann, 1948). More recently, however, there has been growing interest in changing this image of families with schizophrenia members through work on psycho-education and family participation in the treatment of schizophrenia. Today, most patients are treated as outpatients and the majority stay with their families (Schooler et al. 1995). Caring for someone with schizophrenia may, however, be a considerable burden for families. There is evidence that about two-thirds of family caregivers feel burdened (Fadden et al. 1987; Kuipers, 1993; Winefield and Harvey, 1993). They experience emotional and economic strain and often suffer from various health problems themselves. All this could fit with the theme of detachment which emerged from some of the relatives' narratives in this study, and yet this sense seemed to link particularly closely to the belief which the patient had designated as most important to him or her.

Relatives of people with schizophrenia are no longer stigmatised as having caused the illness. In fact, they are considered partners in treatment who need the proper tools. Some studies have suggested that well informed relatives could be engaged in acting as co-therapists (Lefley and Johnson 1990; Boker 1992; Bauml 1993) and might thus help to improve patients' compliance (Kissling 1994). Thus, various family intervention programmes have been developed, such as family therapy (Tarrier et al., 1988; Hogarty et al., 1991; McFarlane et al. 1995a), educational lectures for relatives (Smith and Birchwood, 1987; Tarrier et al., 1988; Canive et al., 1993), Psycho-educational relatives' groups (Leff et al. 1990; Posner et al., 1992; Baum et al. 1996), group therapy for them too (Kottgen et al., 1984 ; Lewandowski and Buchkremer, 1988) and counselling groups for relatives (Vaughan et al., 1992; Sz mukler et al., 1996; Buchkremer et al., 1997). A first step in such approached, however, lies in

engagement of the relatives, and in my study, while it was clear that a few relatives were keen to engage, the majority were not. This too needs more understanding. Although numerous studies have demonstrated positive results, the inclusion of relatives in the treatment of people with schizophrenia is still not routine, and we need to know how far this may follow from a sense of isolation felt by relatives – if the ones who did participate felt isolation and disconnection, it is at least plausible that an even greater sense of disconnection may partly explain the high participation failure rate among relatives in this study. If, as seems likely, with respect to chronically ill patients, staff feel disconnected too, then there is no-one to reach out to engage families. The model developed in this study for understanding communication about delusions is worth further empirical testing because so many studies have shown the value of full family engagement if it can be achieved (e.g. Mari and Streiner 1996; Pharoah et al. 1999). A meta-analysis of 25 studies showed that the relapse rate can be reduced by 20% if relatives are included in the treatment of patients with schizophrenia; if for longer than 3 months, the effect was particularly marked (Pitschel Walz et al., 2001)

As for staff in the current study, like relatives, they experienced disconnection. A study by Heresco-Levy (1999) examined the relationship between staff rejection and criticism and characteristics of patients suffering from chronic treatment-refractory schizophrenia. They found significant correlations existed between staff rejection levels and scores for the Positive and Negative Syndrome Scale PANSS cognitive factor and the Nurses' Observation Scale for Inpatient Evaluation (NOSIE) manifest psychosis factor. It also found that older nursing staff tended to view patients as more irritable and manifestly psychotic. Critical and emotionally over-involved attitudes between staff and patients result in a less effective communications and lead to disconnection. Considerable overlap exists between the problems that staff and relatives have in dealing with chronically ill patients (Creer et al . 1982). Research

has been extended to include therapeutic relationships with staff. It was hypothesised that staff who work with and have long term relationships with chronic schizophrenia patients might share not only the problems faced by relative caregivers, but also some of their attitudes (Kuipers, 1996). In one study Heinssen et al., (1993) staff scores correlated significantly with patients' current instrumental functioning, hostility, uncooperativeness, and impulsivity. Most of the patients assessed in these studies had chronic schizophrenia and were in hostels or day hospital units and active in rehabilitation programmes –so in this respect similar to the patients in my study. A striking omission from any of these studies, however, is the impact of delusions on these relationships, which I have tried to remedy in my study.

## **6.7 Limitations and strengths**

### **6.7.1 Sample and design method**

Patient participants were drawn from general and forensic psychiatric inpatient units. Although data collection was over a 36 month period, the eligible group of patients was only 73 in total, as turnover was low in any inpatient unit for people with schizophrenia. Of potentially eligible patients, however, only 36 consented to participation and completed the schedules. Both the nature and the size of the sample may have affected findings, the former in terms of generalisability and the latter limiting statistical analysis in the quantitative components of the study. Although we could access little information about eligible patients who had refused to participate, there was little difference between our participant patients and those refusing on the basic criteria of gender - most participants and non-participants alike were men and recruitment from general and forensic hospital units was similar. Furthermore, participation rate was even lower for relatives.

The limitations were partly imposed by the ethics approval, which required that the first interview with the patients (on which this study is based) took place in an inpatient unit. Nonetheless, the sample size for the three groups in itself is, in some ways, an important finding; some of the patients who did talk to me about their delusions, were resistant to allowing another researcher to contact that relative or staff. Moreover, where relatives or staff were nominated, only half of them felt able to talk about their communications with the patient. The pattern of difficulties in recruiting other participants is an important finding, tending to confirm the likelihood of difficulties in crucial social and clinician relationships and indicating that exploration of such difficulties is important.

Our low recruitment rate may also mean that the main findings are drawn from a group of people who may be unusual. These people with psychosis had managed not only to maintain a willingness to talk about their illness difficulties, but were also willing to talk with a researcher about this. Therefore, the issue of potentially biased sample may limit the generalisability of results to a wider population.

It was particularly notable that only few people from the patient's family could be engaged in this study. I had concerns that, in order to recruit as many patients as I did, the inclusion criterion on how long the patient should have been in hospital had to be relaxed: in the beginning we thought to include only resident inpatients in forensic or general psychiatric inpatient units at time of ascertainment who had been admitted within the last month – to try and ensure that regular contact with families was the rule, but in order to continue recruiting, we had to extend the residency criterion to 6 months. This might have increased distance from the relatives. However, the patients insisted that they were still talking to the nominated relative about their belief, so the length of admission alone is unlikely to have limited this

aspect of the study. Another limitation might lie in the different sources of recruitment. However the samples from general and forensic hospital units were very similar in chronicity and other illness features. Insofar as a diagnosis of schizophrenia *per se* is relevant, this did distinguish forensic from general hospital patients.

I was denied access to patients who were deemed too ill by staff to participate. It is highly likely that features of the illness interfered with participation of those who we were not allowed to approach; they may have been too paranoid or too troubled in other ways about their symptoms to talk with me. It could be argued that patients who were eligible and refused could be considered not willing to talk about their delusional beliefs but not those deemed by hospital staff as too ill to be approached as we simply don't know about them. Among inpatients with chronic psychosis only 54% appeared willing to speak about their delusions at this time. This is a limitation of any study which requires consent of the participants. However, the absolute frequency with which patients are talking about their delusions is less important than the finding that at least a substantial minority of even chronically ill patients do so, and yet may find that relatives or staff are not listening.

Although the high proportion of potential candidates who refused to participate may have contributed to selection bias for the more quantitative aspects of the study, this affects the qualitative work to a lesser extent. Here the outcome was a testable theory or model, and not only did that emerge for the patients, but the patients' model of communication had key features in common with the model emerging from what relatives and staff independently reported to researchers who were blind to everything that the patient had reported other than the content of his or her most important belief. One additional limitation could be that the study was limited to three hospitals two general and one forensic psychiatric hospital inpatient units in South

Wales, and thus the catchment populations may not represent the population of larger cities.

### **6.7.2 Measures implemented in study**

The use of The Maudsley Assessment of Delusion Schedule (MADS; Taylor et al., 1994) gives strength to our study as it is reliable assessment of the delusion which the patient selects as his or her most important belief along nine dimensions. Although the interview should take no more than 20 minutes to complete, it took much longer with some patients who were particularly ill and could become distracted. The addition of the supplementary assessment of interactions about delusions also added further strength. Also use of the Comprehensive Psychopathology Rating Scale (CPRS; Asberg et al, 1978) to assess patient's symptoms including delusion(s) provided a psychopathological context for the main delusion.

The model of the communication in relation to the patient's delusion according to each party independently, was allowed to emerge from narrative materials, and these were not always extensive. Informant accounts on the designate most important delusions had to be supplemented with material from the five minute speech sample (FMSS; Magana et al, 1986). This had been used to screen for expressed emotions (EE). It is, however, a valid and reliable tool, with data collected on the assumption of qualitative analysis as well as the high/low EE determination.

## **6.8 Implications for clinical practice**

Talking about delusions, regardless of characteristics of the patient's delusion, is common. My study adds some weight to that claim, but shows also how rarely day-to-day conversations with relatives or staff have previously been researched. As patients generally do want to talk about their delusions, but relatives and staff seem to be at least somewhat avoidant of doing so with them, a greater understanding of what these communications may mean for the various parties seems to be important and should get more attention.

It would seem an ideal to give more time to relatives and friends of patients, to listen to their views, but in my study, although invited to come and do so, and reasonable expenses were offered, few came. This needs further exploration, but the model of communication which emerged from talking with those who did come suggested that further exploration of and perhaps help with their sense of disconnectedness might be the key. They may have crucial information about the patient's delusion and its impact.

Some studies have shown that insofar as violence complicates psychosis, people the patient knows well are the most likely to become victims of that violence (Johnston & Taylor, 2003), and yet relatives and friends may also be crucial in the treatment process and, at the least, often become default carers. Patients, their families and clinicians could all benefit from a better understanding of how to get a full picture of the nature and consequences of delusions in each case.

The relatives do want to know how to respond to their patient if he or she starts talking about delusions. This remains an issue as it is clear that research on relatives–patient communication about delusions is in its infancy. Nevertheless, our findings may help clinicians to observe that the difficulty in recruiting relatives and staff to participate in the study may add further evidence that this is a neglected area of research because they tend to be rather avoidant.

The findings of this study may indicate that staff should routinely make more efforts to engage relatives who the patients regard as people to whom they confide about their most important delusion and other problems, and that staff themselves might ensure that their opportunities for reflective practice about such matters are safeguarded. Even if cognitive-behavioural therapy were to achieve no more than allowing discussion of delusions in relative safety, there may be something in the techniques that might be taught to the sufferer's relatives and friends to help safeguard them all. It may not take much training for lay carers to acquire skills, and some of the CBT programmes explicitly incorporated some family work to assist in reinforcing the patient's newly learnt skills (e.g. Durham et al., 2003).

The model developed in this study is worth further empirical testing because many other studies have shown the value of family engagement if it can be achieved, properly including proper communication (e.g. Pharoah et al., 1999). A meta-analysis of 25 studies showed that the relapse rate can be reduced by 20% if relatives are included in the treatment of patients with schizophrenia (Pitschel Walz et al., 2001). Improving services for people with delusions is dependent on an understanding of the complex interplay of delusional experiences, social interactions and other propels experiences such as detachment/ change. Subsequent research undertaking a



longitudinal study could show differences whether the models are characteristic only of people with delusions and their contacts during chronic illness, or whether this sense of intense intrusiveness and change emerges even in acute delusional states. This can clarify both the timing and sequencing of critical developments.

As mental health problems including psychotic disorders are often chronic, the social interaction between the three parties may play a central role in the patient's involvement in treatment and their adherence to treatment recommendations and longer-term outcome. According to the proposed models of this study the all people with delusions should be allowed to talk about them with others. In fact they should be encouraged to talk about their experiences of intrusiveness of these beliefs. However, this should be only carried out within a clinical framework that ensures safety for all parties.

## 6.9 Implications for future research

This study examined the frequency and nature of patient interactions about their delusional belief, as reported by patients, patient-nominated social and professional informants, and also examined the congruence and dissonance between them. On the one hand it confirms that talking about delusions is sufficiently common to merit study and on the other that such study is rare. My models of communication, drawn from narrative data are internally consistent, but the sample was highly selected in being only with hospitalised patients, so people with chronic and severe illnesses. Next steps would include testing communications between patients in community settings and their clinicians and significant others. There was no research related distress and no adverse reaction at all from any patient, relative or staff among those who were interviewed in my study, so it is likely to be perfectly safe to interview community based people. Further, a longitudinal study, ideally starting with people in a first episode of schizophrenia would be necessary to develop understanding of the sequencing of delusional intrusiveness and sense of change and/or disconnectedness. My work was entirely based on self-report, and some observational work would be valuable.

With regards to the proposed models, the present study marks a starting point in clarifying and describing communications among people with psychosis. It adds a systematic, qualitative, three-way perspective on communications about delusions. My main interest for future work would be in whether the findings could inform a novel intervention for such people, who seem to have got stuck, their symptoms not responding to conventional treatments and threatening to cut them off from adequate social and clinical support if they have not already done so. Application of fuzzy logic models to group intervention development may be most useful, given the patients'

sense of personal transformation. My models would then suggest that the key outcome variables would be that the patient's sense of a fundamental change in him- or her-self is reduced, the most important delusion is experienced as less intrusive and the relatives and staff are able to rate the patient as less disconnected. Such interventions would be developed with the advice of recovering patients, their relatives and staff in focus groups. It is vital that the prospective users of an intervention find it acceptable, otherwise few would stay the course. Ideally, I would have been able to go back to staff who participated in this study for a preliminary discussion of my models and their implications in this context. The resultant intervention guidance would then be presented to a second focus group, and developed further. The resultant intervention would then need to be tested for feasibility in a real clinical setting before being submitted to a full trial.

I would envisage first steps with any intervention being conducted in a clinical setting because of the paucity of data on the impact of talking about delusions, but a further goal would be to develop a simple way of talking with people about their delusions that would help relatives too.

## 6.10 Conclusions

No previous study has investigated the communication about delusions between these three parties in this way, and there is very little research of any kind into ordinary, everyday communication about delusions between patients and their relatives or patients and staff. This study has confirmed that patients who have at least one delusion are willing to talk about it with other people. Most will talk to either staff or relatives about their delusions, but some have clear preferences.

Where at least two perspectives on the characteristics of the delusion were available, there was good agreement between all parties on some of its defining characteristics, particularly content, but the nature and extent of disagreement on some aspects of the beliefs suggests at least the possibility that communication about delusions needs improving. Where there were discrepancies between reporting, it was not possible to say which account was the more accurate, but it is of particular concern that was 45% dissonance between patients and staff on something as serious as the view that the delusion had led to harm to self or others.

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## **Appendices**

## Appendix 1: Performa for data extraction (mini-review protocol)

### A Mini-Review Protocol

#### Background

##### **Types of communication about delusions among people with psychosis who become violent**

It is well known that the rate of violence among people with psychosis is higher than in the general population (Taylor, 2008). For those with psychosis, delusions are common and found to be the main trigger to violence (Taylor et al, 1998). A number of factors are thought to characterise those delusions which lead to violence from those which do not. Response to hypothetical challenge in a research setting is considered to be among them (Taylor, 2006). Nevertheless, little is known on communication about delusions.

The purpose of this review is to find published literature on routine communication about delusions between people who are suffering from delusions/patients with psychosis and people in their social circle and/or clinicians they consult.

##### **Method:**

A comprehensive search was conducted of literature published from 1960s-2009, using MEDLINE, PsychINFO, EMBASE, and PubMed electronic databases, to identify relevant articles.

#### Review question(s)

##### *Primary question/ hypothesis:*

Do people/patients with delusions talk about them to other people?

##### *Secondary question(s):*

- What proportion of them talk to other about their delusions?
- To whom do they talk?
- What do they say?
- Do patients and listeners report the same things about the conversation?
- Is anything reported about the effects of such conversations –
  - on the delusions?
  - on aspects of behaviour, including violence?
- Are any barriers reported to such conversations?
- Are there any reports of such conversations being beneficial?
- Are there any reports of such conversations being harmful?  
and therefore, can protective factors be identified?
- Can factors which may have an adverse effect on the delusions or behaviour be identified?

## Inclusion and exclusion criteria

Selection criteria	Inclusion	Exclusion
Population:  Psychotic patients with delusion(s)	People experiencing delusion(s) as defined by DSM IV or ICD-10  Inpatients, outpatients (general and forensic) and, people who may not yet have become patients, but are regarded as having psychotic symptoms  Age: $\geq 18$ years	Children and Adolescents  Patients with learning disability and/or gross brain damage
Intervention(s)	N/A The focus is on ordinary communication about the beliefs	Any kind of specific treatment (biological or psychological)
Outcome(s)	- Change in delusion(s) following the communication.  - Change in behaviour following the communication  -Any other change following the communication	
Comparison(s)	N/A (no comparisons to be made)	
Study design(s)	- Any study which has some indication of change in delusions or behaviour in relation to communication. - Longitudinal studies Self report studies providing they incorporate some reference to change	- Cross-sectional studies  - Single case studies  - Specific interventional studies (e.g. trials)
Publication type(s)	- Only peer reviewed journals - key book(s) on	

	phenomenology, e.g. General Psychopathology 1962 by Jaspers, will be accessed to refine definitions of beliefs, or to check reference lists	
Publication year(s)	From 1960s- 2009	
Language(s)	Articles in English Where an article is identified in another language but has an abstract in English, the abstract will be read and consideration given to seeking a translation	Articles in a language other than English and without an abstract in English

### Search strategy

Terms to be used	Thesaurus	Free-text
Population	Communication Interaction Talking Psychosis Psychotic symptoms Schizophrenia Delusions False beliefs	
Intervention(s)	N/A	
Outcome(s)	Change in belief and/or behaviour	
Comparison(s)	N/A	

Limits to be applied	
Study designs	All studies with any longitudinal component, whether prospective, or retrospective report

Publication types	Peer reviewed journals	
Date of publication	1960s- March 31 <sup>st</sup> 2009	
Language	English	
Other	Article recognised of likely relevance as the abstract has been translated in to English, however, the prospect of translation will depend on the language concerned.	
<b>Sources to be searched</b>		
Evidence based databases	The Cochrane Library	
Core health databases	MEDLINE 1950-2009 EMBASE 1980-2009	
Related disciplines databases		
Subject specific databases	British Nursing Index 1985-2009 PsycINFO 1806-2009 PubMed	
'Grey literature' sources	Google and Google Schooler	
Other methods	- Citation searching - Contacting organisations & experts - Hand searching	

## Quality assessment

I am not sure if I want to exclude any primary study at this stage on the ground or aspects of methodology at the moment because I don't expect/ could not find many relevant studies!

## Data extraction

I wonder if I can avoid citation bias.

## Proposed data synthesis

I will present the findings of the studies in tables and write a commentary.  
I think it very unlikely that the data will be sufficiently systematically collected that a meta-analysis is possible.

## Project timetable

Task	When by?	Status
1. Focus question		
2. Draft protocol		
3. Conduct scoping search		
4. Finalise protocol		
5. Conduct full searches		
6. Order papers		
7. Select articles		
8. Quality assessment		
9. Data extraction		
10. Data synthesis		
11. Write report		

## **Appendix 2: Research ethics approval (details and letter of approval)**

# *National Research Ethics Service*

## **North Somerset & South Bristol Research Ethics Committee**

Assembly Rooms UBHT Headquarters Marlborough Street Bristol BS1 3NU Tel: 0117 928 3613 Email: [naaz.nathoo@ubht.nhs.uk](mailto:naaz.nathoo@ubht.nhs.uk) Facsimile: 0117 928 3724

09 November 2007

Professor Pamela J Taylor

Professor Forensic Psychiatry/Honorary Consultant Forensic Psychiatrist

Cardiff University/Bro Morgannwg NHS Trust

Department of Psychological Medicine

School of Medicine, Cardiff University

Heath Park, Cardiff

CF14 4XN

Dear Professor Taylor

Full title of study: Delusions, social interaction and violence: A study to evaluate the effect of social interaction on the conviction and persistence of delusional beliefs and likelihood of delusionally driven violent acts.

REC reference number: 07/H0106/148

Thank you for your letter of 03 October 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 08 November 2007. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.



## Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		OS August 2007
I Investigator CV		
Protocol	1 (given by REC Coordinator)	07 August 2007
Covering Letter		21 August 2007
Summary/Synopsis	for GP	
Letter from Sponsor		26 June 2007
Peer Review	Prof. P Rogers	09 August 2007
Peer Review	Prof. S Estroff	09 August 2007
Compensation Arrangements		01 August 2007
Questionnaire	PEESS	
Questionnaire	The LEE Scale	
Questionnaire	MADS	I
Questionnaire	SCL-90-R	
Questionnaire	MADS informant interview	
Questionnaire	Family Q.	
Questionnaire	CPR Scale	
Questionnaire	EPQ-R	
GP/Consultant Information Sheets	1 (given by RECC)	07 August 2007
I Participant Information Sheet	2.03 (informant - significant other)	07 August 2007
! Participant Information Sheet	2.04 (informant - significant other)	02 October 2007
Participant Information Sheet	1.04 - patient	02 October 2007 !
Participant information Sheet	3.03 (staff informant)	02 Octooer 2007
Participant Consent Form	3.03 - staff informant	02 October 2007
Participant Consent Form	1.04 - patient	02 October 2007
Participant Consent Form	2.04 (significant other)	02 October 2007
Response to Request for Further Information	103 OctODer 2007	

## R&amp;D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborates accordingly.

Guidance on applying for R&D approval is available from <http://www.rdf.oru.nhs.uk/rdfom.htm>.

## Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## After ethical review

Now that you have completed the application process please visit [www.nres.npsa.nhs.uk](http://www.nres.npsa.nhs.uk) (After Review). Here you will find links to the following

a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known, please use the feedback form available on the website <https://www.nationalres.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx>.

b) Please refer to the attached Standard conditions of approval by Research Ethics Committees regarding submission of Progress Reports, Safety Reports, Amendments and End of Study/Project procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nationalres.org.uk](mailto:referencegroup@nationalres.org.uk).

07/H0106/148 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project Yours sincerely

Mr Richard Ashby Chair

*Enclosures: List of names and professions of members who were present at the meeting*

*and those who submitted written comments Standard approval conditions*

Copy to:

Dr K J Pittard-Davies '

Head of Research Policy & Management

Research & Commercial Division

Cardiff University

7<sup>th</sup> Floor. 30-36 Newport Road

Page 3

Cardiff CF24 ODE

North Somerset & South Bristol Research Ethics Committee

Attendance Sub-Committee of the REC meeting on 08 November 2007

Name	i Profession	Present	Notes
Mr Richard Ashby	Chartered Manager - Lay	Yes	1 1
Mr Stephen Brown	Director of Pharmacy	Yes	
Dr Pamela Cairns	<sup>1</sup> Consultant Neonatologist	Yes	

# RESEARCH IN HUMAN SUBJECTS OTHER THAN CLINICAL TRIALS OF INVESTIGATIONAL MEDICINAL PRODUCTS

## Standard conditions of approval by Research Ethics Committees

### 1. Further communications with the Research Ethics Committee

1.1 Further communications during the research with the Research Ethics Committee that gave the favourable ethical opinion (hereafter referred to in this document as "the Committee") are the personal responsibility of the Chief Investigator.

### 2. Commencement of the research

2.1 It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.

2.2 In the case of research requiring site-specific assessment (SSA) the research may not commence at any site until the Committee has notified the Chief Investigator that the favourable ethical opinion is extended to the site.

2.3 The research may not commence at any NHS site until the local Principal Investigator (PI) or research collaborator has obtained research governance approval from the relevant NHS care organisation.

2.4 Should the research not commence within 12 months, the Chief investigator should give a written explanation for the delay. It is open to the Committee to allow a further period of 12 months within which the research must commence.

2.5 Should the research not commence within 24 months, the favourable opinion will be suspended and the application would need to be re-submitted for ethical review.

### 3. Duration of ethical approval

3.1 The favourable opinion for the research generally applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Committee should be notified.

#### A. Progress reports

4.1 Research Ethics Committees are required to keep a favourable opinion under review in the light of progress reports and any developments in the study. The Chief Investigator should submit a progress report to the Committee 12 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.

4.2 Progress reports should be in the format prescribed by NRES and published on the website (see

<http://www.rres.npsa.nhs.uk/applicants/review/3fter/proaress.htm#submissi3n> )

SOPs version 3.0 aateo June 2005: v3.1 minor editing to NRES name change 1 April 07 SL-AC2 Approval conditions (research other than CTiMP)

4.3 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss the progress of the research.

### 5. Amendments

5.1 If it is proposed to make a substantial amendment to the research, the Chief Investigator should submit a notice of amendment to the Committee.

5.2 A substantial amendment is any amendment to the terms of the application for ethical review, or to the protocol or other supporting documentation approved by the Committee, that is likely to affect to a significant degree:

- (a) the safety or physical or mental integrity of the trial participants
- (b) the scientific value of the trial
- (c) the conduct or management of the trial.

5.3 Notices of amendment should be in the format prescribed by NRES and published on the website, and should be personally signed by the Chief Investigator.

5.4 A substantial amendment should not be implemented until a favourable ethical opinion has been given by the Committee, unless the changes to the research are urgent safety measures (see section 7). The Committee is required to give an opinion within 35 days of the date of receiving a valid notice of amendment.

5.5 Amendments that are not substantial amendments ("minor amendments") may be made at any time and do not need to be notified to the Committee.

#### 6. Changes to sites (*studies requiring site-specific assessment only*)

6.1 Where it is proposed to include a new site in the research, there is no requirement to submit a notice of amendment form to the Committee. The Site-Specific Information (SSI) form of the application form together with the local Principal Investigator's CV should be submitted to the relevant REC for site-specific assessment (SSA).

6.2 Similarly, where it is proposed to make important changes in the management of a site (in particular, the appointment of a new PI), a notice of amendment form is not required. A revised SSI form to\* the site (together with the CV for the new PI if applicable) should be submitted to the relevant REC for SSA.

6.3 The relevant REC will notify the Committee whether there is any objection to the new site or Principal Investigator. The Committee will notify the Chief Investigator of its opinion within 35 days of receipt of the valid application for SSA.

6.4 For studies designated by the Committee as exempt from SSA, there is no requirement to notify the Committee of the inclusion of new sites.

SOPs version 3.G dated June 2005: v3.1 dated 1 April 07 minor editing to NRES name change SL-AC2 Approval conditions (research other than CTIMP)

#### Urgent safety measures

7.1 The sponsor or the Chief Investigator, or the local Principal Investigator at a trial site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

7.2 The Committee must be notified within three days that such measures have been taken, the reasons why and the plan for further action.

#### 8. Serious Adverse Events

8.1 A Serious Adverse Event (SAE) is an untoward occurrence that:

- (a) results in death
- (b) is life-threatening
- (c) requires hospitalisation or prolongation of existing hospitalisation

(d) results in persistent or significant disability or incapacity

(e) consists of a congenital anomaly or birth defect

(f) is otherwise considered medically significant by the investigator.

8.2 A SAE occurring to a research participant should be reported to the Committee where in the opinion of the Chief investigator the event was related to administration of any of the research procedures, and was an unexpected occurrence.

8.3 Reports of SAEs should be provided to the Committee within 15 days of the Chief Investigator becoming aware of the event, in the format prescribed by NRES and published on the website.

8.4 The Chief investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss any concerns about the health or safety of research subjects.

8.5 Reports should not be sent to other RECs in the case of multi-site studies.

#### 9. Conclusion or early termination of the research

9.1 The Chief Investigator should notify the Committee in writing that the research has ended within 90 days of its conclusion. The conclusion of the research is defined as the final date or event specified in the protocol, not the completion of data analysis or publication of the results.

9.2 If the research is terminated early, the Chief investigator should notify the Committee within 15 days of the date of termination. An explanation of the reasons for early termination should be given.

9.3 Reports of conclusion or early termination should be submitted in the form prescribed by NRES and published on the website.

SOPs version 3.0 Gated June 2005; v3.1 dated 1 April 07 minor editing to NRES name change S--AC2 Approval conditions i research other than CTIMP)

#### 10. Final report

10.1 A summary of the final report on the research should be provided to the Committee within 12 months of the conclusion of the study. This should include information on whether the study achieved its objectives, the main findings, and arrangements for publication or dissemination of the research including any feedback to participants.

#### 11. Review of ethical opinion

11.1 The Committee may review its opinion at any time in the light of any relevant information it receives.

11.2 The Chief Investigator may at any time request that the Committee reviews its opinion, or seek advice from the Committee on any ethical issue relating to the research.

#### 12. Breach of approval conditions

12.1 Failure to comply with these conditions may lead to suspension or termination of the favourable ethical opinion by the Committee.

SOPs version 3.0 dated June 2005; v3.1 dated 1 April 07 minor editing to NRES name change SL-AC2 Approval conditions (research other than CTIMP)

## Appendix 3: Research passport form

### Research Passport

*Please refer to the guidance notes before completing the form.*

<b>Section 1 - Details of Researcher</b> <i>To be completed by Researcher</i>			
1.	Surname: Fadhli		Prof <input type="checkbox"/> Dr X Mr <input type="checkbox"/> Mrs <input type="checkbox"/>
	Forename(s): Karam Adnan		Miss <input type="checkbox"/> Ms <input type="checkbox"/> Other <input type="checkbox"/>
	Home Address: 68 Landmark Place Churchill Way CF10 2HS Cardiff		
	Work Address/Place of Study: Department of Psychological Medicine School of Medicine Cardiff University Heath Park Cardiff CF14 4XN		
	Work Tel: +44(0) 2920743090 Mobile: 07503551949 Email: <a href="mailto:FadhliKA@cardiff.ac.uk">FadhliKA@cardiff.ac.uk</a>		
2.	Date of birth: 1,Januray,1971	Gender: Male X Female <input type="checkbox"/>	
	Ethnicity: Asian background	National Insurance number:	
3.	Professional registration details (if applicable):		N/A X
4.	Employer: or place of study: School of Medicine-Cardiff University		
	Post or status held: MD (Doctor of Medicine) Student		
<b>Section 2 - Details of Research</b> <i>To be completed by Researcher</i>			
5.	What type of Research Passport do you need? Project-specific X Three-year <input type="checkbox"/>		
	<i>If you will be conducting only one project please complete the details below. If you will be undertaking more than one project at any one time, please give details in the Appendix.</i>		
	Project Title: Types of communication about delusions among people with psychosis who became violent		
	Project Timetable: Start Date: 6,Jan,09 End Date: 31,Dec,09		
	NHS organisation(s):	Dept(s):	Proposed research activities:
	NHS Trusts (Cardiff & Vale, ABM University, Avon & Wiltshire NHS Partnership)	Psychological Medicine	Interviewing consenting patients, nominated relatives or staff person; records review
	Other health services: Partnerships in Care		As above
		Manager in NHS organisation:	

### Section 3 – Declaration by Researcher

*To be completed by Researcher*

6.	Have you ever been refused an honorary research contract?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
	Have you ever had an honorary research contract revoked?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
If yes to either question, please give details:		

I consent to the information requested in this Research Passport (including attached documents) being processed and held by authorised staff of the NHS organisations where I will be conducting research.

Signed: \_\_\_\_\_ Date: 13, Feb, 09

*When Sections 1-3 have been completed, the researcher should forward the form to the appropriate person to complete Section 4.*

### Section 4 - Suitability of Researcher

*To be completed by researcher's substantive employer, e.g. line manager, or academic supervisor*

7.	I am satisfied that the above named individual is suitably trained and experienced to undertake the duties associated with the research activities outlined in this Research Passport form.	
	Signed: _____	Date: 16 <sup>th</sup> February 2009
	Name: Pamela J Taylor	Job Title: Professor of Forensic Psychiatry
	Organisation: Scholl of Medicine, Cardiff University	Department: Psychological Medicine
	Address: heath Park, Cardiff CF14 4XN	
	Email: <a href="mailto:taylorpj2@cardiff.ac.uk">taylorpj2@cardiff.ac.uk</a>	

*When Section 4 has been completed, the researcher should forward the form to the appropriate person to complete Section 5.*

### Section 5 - Pre-engagement checks

*To be completed by the HR department of the researcher's substantive employer or registry at place of study*

8.	Can you confirm that a clear criminal record disclosure has been obtained for the above-named individual, with no subsequent reports from the individual of changes to this record?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
<i>If yes, please provide details of the clear disclosure</i> Date of disclosure: Type of disclosure: Organisation that requested disclosure:		
9.	Have the pre-engagement checks described below been carried out with regard to the above-named individual?	

■ Employment/student screening: <ul style="list-style-type: none"> <li>○ ID with photograph</li> <li>○ two references</li> <li>○ verification of permission to work/study in the UK</li> <li>○ exploration of any gaps in employment</li> </ul>		Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>
■ Evidence of current professional registration		Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
■ Evidence of qualifications		Yes <input type="checkbox"/> No <input type="checkbox"/>
■ Occupational health screening		Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Signed:		Date:
Name:		Job Title:
Organisation:		Department:
Address:		
Email:		
Please return the form to the researcher.		

## Section 6 - Instructions to applicants

*To be completed by Researcher*

*Please indicate which of the following documents are attached to this Research Passport:*

Current curriculum vitae, including details of qualifications, training and professional registration (please use the template C.V. at <a href="http://www.rdforum.nhs.uk/docs/template_cv.doc">http://www.rdforum.nhs.uk/docs/template_cv.doc</a> )	Yes X No <input type="checkbox"/>
Researcher's copy of criminal record disclosure (if question 8 is answered Yes)	Yes <input type="checkbox"/> No X N/A <input type="checkbox"/>
Evidence of occupational health screening	Yes <input type="checkbox"/> No X N/A <input type="checkbox"/>
Appendix	Appendix numbers:  N/A <input type="checkbox"/>

*Please send the completed form and original documents to the lead R&D office. The completed form and original documents will be returned to you. This package of documents will form your completed Research Passport. You may, where relevant, provide the Research Passport to other NHS organisations.*

**You must inform all NHS organisations that have received this Research Passport of any changes to the information supplied above. Failure to do so may result in withdrawal of your honorary research contract or letter of access. As part of the quality control procedures for the Research Passport, random checks on the accuracy of the information held on this Research Passport may be made.**



<b>Section 7</b>			
<b>This section should be completed by HR in the lead NHS organisation, only if additional checks are undertaken</b>			
Having undertaken the necessary additional pre-engagement checks, I am satisfied that the above named researcher is suitable to carry out the duties associated with their research activity outlined in this Research Passport.			
Signed:		Date:	
Name:		Job Title:	
Organisation:		Department:	
Email:			
<b>Section 8 - For Office Use Only</b>			
<i>This section should be completed by the NHS R&amp;D office that received the initial application. The NHS R&amp;D office must countersign and date retained photocopies of the documents. The grey section must be completed before returning the form to the applicant.</i>			
CV reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/>	Training?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Evidence of qualifications?	Yes <input type="checkbox"/> No <input type="checkbox"/>	Appendix pages reviewed?	Numbers:
Registration details reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	Occupational health evidence reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Criminal record disclosure reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	Date of disclosure:	Certificate No:
Enter Electronic Staff Record Number (if issued):			
Valid Research Passport issued: Project specific <input type="checkbox"/> Three-year <input type="checkbox"/>			
Signed:			Date:
Name:			
Date Honorary Research Contract/letter of access issued ( <i>delete as appropriate</i> )			

<i>This section should be completed by the NHS R&amp;D office receiving the valid Research Passport. The NHS R&amp;D office must countersign and date retained photocopies of the documents. The original Research Passport and documents should be returned to the applicant.</i>			
CV reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/>	Training?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Evidence of qualifications?	Yes <input type="checkbox"/> No <input type="checkbox"/>	Appendix pages reviewed?	Numbers:
Registration details reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	Occupational health evidence reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Criminal record disclosure reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	Date of disclosure:	Certificate No:
Checked Electronic Staff Record: Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>			
Signed:			Date:
Name:			
Date Honorary Research Contract/letter of access issued ( <i>delete as appropriate</i> )			
<b>Passport Appendix. List of projects and amendments</b>			

Appendix

Number:

If you are applying for a three-year Research Passport, please use this section to enter details of projects and activities that will be covered by this Research Passport. Once you have a complete Research Passport, you may add details of subsequent projects during the three years that this Research Passport is valid.

If you are applying for a project-specific Research Passport, but need to subsequently add further sites to the project, please enter the details below.

Whenever you add further details, the full Research Passport and accompanying documents must be submitted to the relevant NHS organisations.

Title:		Start Date:	End Date:
NHS organisation(s):	Dept(s):	Proposed research activities:	Manager in NHS organisation:

### Amendments to the Research Passport

Please state what these are, e.g. they might be a change in name or employment details, or a change in research activities.

Please check with the NHS organisation where you are undertaking your research if you are unsure whether you will need a new Research Passport.

Date	Old Details	New Details	Office use only NHS R&D signature

**Appendix 4:** Request letter to all consultant psychiatrists seeking participation and permission



Dear All,

We would be most grateful for your help in some new research into communication about delusions. We would like your permission to approach any of your in-patients, soon after admission, who at that time have at least one delusion and who you think might be willing to speak with us about it. The research has been approved by the NPSA SW Multi-Centre Research Ethics Committee and is sponsored by Cardiff University. We are particularly interested to learn more about what patients with delusions say about them to any relative or friend in whom they feel they can confide about them, and what they say to a similarly trusted clinician. We also want to know something about how they think those people have responded, and, in turn, how those people consider they actually did respond. Finally, we are interested in the effect of any of this on the belief itself and/or on any behaviour that follows from the belief.

So long as you are content for us to approach your patients, we will liaise with the ward manager about doing so. We will take formal written consent from all those who indicate they would be happy to participate before proceeding to interview. I attach a copy of the information sheet for patients, and also, in case you are interested, a detailed protocol. In practice, it will generally be **Dr Karam Fadhli** who attends to seek consent and to conduct the interview with the patient. There are two other

principal researchers involved– Ms Emma Dunn and Dr Loli Bragado, whose principal task it will be to talk with the family or professional informants.

If you would like any further information about the study, please do not hesitate to ask me. I do hope you feel able to help us in this way. We will try to make the process as unobtrusive as possible and to ensure that as far as possible, any participating patient feels that they have had a good experience if they do the interviews with us.

I look forward to your confirmation that we may proceed, and, if so, whether you have any special conditions you would like us to follow.

Best wishes,

Pamela

Pamela J Taylor  
Professor of Forensic Psychiatry  
Department of Psychological Medicine  
Wales College of Medicine, Cardiff University  
Heath Park  
Cardiff CF14 4XN, UK,

Tel: +44 (0) 29 2074 3090

Fax: +44 (0) 29 2074 7839

**Appendix 5:** Follow up communications for consultant psychiatrists participation in the study

**To:** "Karam Fadhli" <FadhliKA@cardiff.ac.uk>  
**From:** "Lindsey Bond" <bondlc@Cardiff.ac.uk>  
**Date:** 27/03/2009 20:06  
**Subject:** Re: Fw: RE: List of consultants

Hi Karam

I've seen a few more since I emailed you:-

Dr Elameer - says he has already spoken to you and is happy to participate - he has given you his mobile number and is happy for you to contact him again to discuss patients.

Dr Peter Williams - says he has already agreed (possibly spoke to Professor Taylor directly).

Dr Adeline Cutinha - has not replied but is willing to participate - she stressed that all approaches to patients must be made through the ward manager.

Best wishes.

Lindsey

**>>> Karam Fadhli <FadhliKA@cardiff.ac.uk> 27/03/2009 14:04 >>>**

Hi Lindsey

I am really really thankful for your help.  
I agree with you about David Seeley.  
Thank you so much indeed, highly appreciated.  
With best regards

Karam

-----"Lindsey Bond" <bondlc@Cardiff.ac.uk> wrote: -----

**To:** "Karam Fadhli" <FadhliKA@cardiff.ac.uk>  
**From:** "Lindsey Bond" <bondlc@Cardiff.ac.uk>  
**Date:** 03/27/2009 11:46AM  
**Subject:** Fw: RE: List of consultants

Hi Karam

I have seen several consultants today & reminded them of your email.

Maria Atkins says she has replied already (possibly directly to Professor Taylor, she couldn't remember who she emailed about this). Cath Curran will reply - she has some concerns and wants to talk to her team before she replies. Izabella Jurewicz says she would be supportive of this as Clinical Director, and would be supportive of her patients on E5A being involved, on the understanding that any approach is made via the nursing staff and ward manager in the first instance, who can then discuss the appropriateness of any individual patient being involved with Dr Jurewicz first. Najeed Khalid says he has spoken to you on the telephone about this already. Andrew Smith is happy in principle, on the understanding that you email him directly before approaching any individual patient so that he can let you know if he agrees on an individual basis (email:

Andrew.Smith@cardiffandvale.wales.nhs.uk)

(By the way, David Seeley is on your list but I'm not sure if he should be - he is currently based at Cardiff Prison so I think it might be difficult to get access to his patients!)

I'll let you know if I see any other consultants today.

Best wishes.

Lindsey

**>>> Karam Fadhli <FadhliKA@cardiff.ac.uk> 26/03/2009 10:59 >>>**

Dear Lindsey

As I promised you last week, I am sending the list of consultants, which I got only yesterday, that we would like to approach their patients in our study ("Delusions, Social interactions and Violence" lead by Prof Pamela Taylor). Kindly find attached a copy of the list.

All of the consultants in the list have already received email about our study asking them for

their help. The email was circulated by Mary Tong (Dr John Lewis' secretary) about a month ago and we had only few replies.

I understand that you may see some/all of the consultants at the WPG Centre.

We, the group working on our study, would be very grateful if you could only remind any of them you meet.

As you know people can forget and need a reminder!

Many thanks for your help and I do appreciate that indeed.

Kind Regards

Karam

Dr karam Fadhli  
Doctoral candidate to Prof Pamela Taylor  
Department of Psychological Medicine  
School of Medicine, Cardiff University  
Heath Park, CF14 4XN, UKTel  
+44(0)2920743090 Mob +44 (0)7503551949

-----Forwarded by Karam Fadhli/wpckaf/CardiffUniversity  
on 03/26/2009 10:29AM -----

**To: "Karam Fadhli" <FadhliKA@cardiff.ac.uk>**  
**From: "TONG Mary" <Mary.Tong@CardiffandVale.wales.nhs.uk>**  
**Date: 03/25/2009 09:36AM**  
**Subject: RE: List of consultants**

These are the consultants who were contacted. Hope this is the information you need.

Best wishes

Mary

Mary Tong

PA/Secretary to Dr John Lewis Associate Medical Director  
Consultant Psychiatrist

Tel: 02920 336592 Fax: 02920 336375

**From:** Karam Fadhli [<mailto:FadhliKA@cardiff.ac.uk>]  
**Sent:** 25 March 2009 09:31  
**To:** TONG Mary  
**Cc:** taylorpj2@Cardiff.ac.uk  
**Subject:** RE: List of consultants

Dear MS. Tong,

Thank you for your prompt reply.

I would be really grateful if you could send me the list of only the consultants who were contacted. By that I can know who responded to us and who did not. So, perhaps I can remind them later.

Many thanks with best wishes,

Karam

-----"TONG Mary" <Mary.Tong@CardiffandVale.wales.nhs.uk>  
wrote: -----To: "Karam Fadhli"  
<FadhliKA@cardiff.ac.uk>  
From: "TONG Mary" <Mary.Tong@CardiffandVale.wales.nhs.uk>  
Date: 03/24/2009 02:21PM  
Subject: RE: List of consultants

Dear Dr Karam Fadhli  
Thank you for your email.  
The Llandough consultants are included in the list.

Dr Khalid's email  
is [Najeeb.Khalid@cardiffandvale.wales.nhs.uk](mailto:Najeeb.Khalid@cardiffandvale.wales.nhs.uk)  
Dr Elameer is  
[Mohammed.Elameer@cardiffandvale.wales.nhs.uk](mailto:Mohammed.Elameer@cardiffandvale.wales.nhs.uk)

I hope this is the information you need. Best wishes.

Mary

Mary Tong  
PA/Secretary to Dr John Lewis Associate Medical Director  
Consultant Psychiatrist  
Tel:02920 336592Fax:02920 336375



**From:** Karam Fadhli [<mailto:FadhliKA@cardiff.ac.uk>]  
**Sent:** 23 March 2009 15:09  
**To:** TONG Mary  
**Cc:** taylorpj2@Cardiff.ac.uk  
**Subject:** List of consultants


Dear Ms. Tong I received from Mrs Ceri Allen (Professor Pamela Taylor' secretary) the list of consultants who were contacted earlier regarding our study project (Delusions, social interaction and violence). List is attached with this email. I noticed that the list included all consultants from Whitchurch Hospital and not Llandough. Some of the consultants who are appropriate for our study and we would like to approach were not included, for example, Dr Najeeb Khalid and Dr Moudi Elameer.

I would be extremely grateful if you could send me the complete list of the consultant whom you contacted. Many thanks in advance

Best wishes  
Karam

Dr karam Fadhli  
Doctoral candidate to Prof Pamela Taylor  
Department of Psychological Medicine  
School of Medicine, Cardiff University  
Heath Park, CF14 4XN,  
Tel +44(0)2920743090 Mob +44 (0)753551949

## Appendix 6: Advertisement posters (1 and 2) for the recruitment procedure



**CARDIFF UNIVERSITY**  
**PRIFYSGOL CAERDYDD**

# How do we talk about delusions?

A study by Cardiff University

**What are we doing?**

We would like to interview patients recently admitted to hospital, who have at least one abnormal belief and who would be willing to talk about how it affects them. There should be no disruption in their normal clinical care or daily routine.

If the patient agrees, we would also like to talk with a relative and a health professional about this as well.

**Any Benefits?**

We hope in the long run that this will help patients, their relatives and staff to talk more safely and helpfully about symptoms.

**Will you help?**

We would be really grateful for your help in telling us about patients who have been recently admitted to one of your wards, who have delusions, and who you think might be willing to talk with us.

Please contact (Direct): Dr Karam Fadhli on **07733 670 677**

My colleagues in this work are: Dr Maria Bragado, Dr Shuja Reagu and Professor Pamela Taylor (Lead Investigator).

Further information: Please do not hesitate to contact one of us.  
Forensic Psychiatry Research Group, Department of Psychological Medicine  
School of Medicine, Cardiff University, Heath Park, Cardiff, CF14 4XN  
Tel: +44 (0)29 2074 4002 Fax: +44 (0)29 2074 3840



## HOW DO WE TALK ABOUT DELUSIONS?

### A study by Cardiff University

#### What are we doing?

We would like to interview patients recently (within a week) admitted to hospital, who have at least one abnormal belief and who would be willing to talk about how it affects them. There should be no disruption in their normal clinical care or daily routine.

If the patient agrees, we would also like to talk with a relative and a health professional about this as well.

#### Any Benefits?

We hope in the long run that this will help patients, their relatives and staff to talk more safely and helpfully about symptoms

#### Will you help?

We would be really grateful for your help in telling us about patients who have been recently admitted to one of your wards, who have delusions, and who you think might be willing to talk with us.

Please contact (**Direct**):

**Dr Karam Fadhli** on 07733 670 677

My colleagues in this work are: Dr Maria Bragado, Dr Shuja Reagu and Professor Pamela Taylor

**Further information:** Please do not hesitate to contact one of us  
Forensic Psychiatry Research Group,  
Department of Psychological Medicine  
School of Medicine, Cardiff University  
Heath Park, Cardiff, CF14 4XN  
Tel: +44 (0)29 2074 4002, Fax: +44 (0)29 2074 3840

## **Appendix 7 Participant information sheet about the study**



### **PARTICIPANT INFORMATION SHEET**

#### **A RESEARCH STUDY TO FIND OUT ABOUT IMPORTANT BELIEFS WHICH ARE ATTRIBUTED TO ILLNESS: DO PEOPLE TALK ABOUT THEIR BELIEFS AND WHAT ARE THE EFFECTS OF DOING SO?**

We are inviting you to take part in a research study. Before deciding if you want to take part or not please read this sheet carefully. The following information will explain why the research is being done and what it will involve. If there is anything that is not clear, please ask us.

Please take time to decide if you would like to take part in this research. A researcher will come and discuss the study with you and answer any questions you might have. Thank you for taking the time to read this information and think about this.

#### **What is the study about?**

Almost all people have beliefs that are important to them, and we sometimes choose to discuss these ideas with others around us. Our beliefs can affect the way we think and feel about things, and the way we act in everyday life. The extent to which other people share our beliefs can vary greatly. Past research has shown that when individuals choose to talk about beliefs with friends, family and others, this can have lots of different effects, sometimes on the beliefs, sometimes on feelings or behaviour associated with these beliefs.

Sometimes beliefs which are very important to a person may be attributed to an illness. We are interested in talking to people who are in hospital about the beliefs which are most important to them, and the effects that these beliefs might have on them, as very little is known about this. We would particularly like to find out more about when it might be helpful or unhelpful to talk with someone else about such beliefs.

If you agree to take part, we would like you to meet with a researcher to talk about your most important beliefs or ideas, and any experiences you might have of discussing them with other people.

#### **Why have I been chosen?**

Everyone resident in a selected group of inpatients units is being invited to take part in this research study if they would like to. It doesn't matter whether you have been in hospital before.

#### **Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form to confirm that you are willing to participate. We will also ask for your permission to have access to your medical

records. This will help us to add information to the research about previous events, assessments or care which may have been recorded, without asking for a lot more time from you.

This research is completely separate from your clinical care. Your decision about the research will not have any impact on the standard of care you receive, or any legal or hospital decisions which involve you.

### **What do I have to do?**

If you are happy to participate then you will be asked to take part in three interviews with a researcher. The first interview will probably last for 60 – 90 minutes and we will use a quiet room on the ward where the conversation can be kept private. The second and third interviews will be arranged for a convenient time about four weeks and eight weeks after the first meeting, and will be shorter (about 45 minutes). You won't need to do anything else apart from meeting with a researcher, and your usual care and activities in the hospital won't be affected in any way.

### **What will happen to me if I take part?**

Apart from meeting the researcher for the interviews, this research should not affect you in any way. We are not testing any drugs or any kind of treatment. We simply want to talk to you to find out more about your experiences.

### **What are the possible disadvantages or risks of taking part?**

We don't think that there are any, but if you have any worries do please tell us about them. If you find talking to the researcher upsetting then please let them know. If you change your mind about participation part way through the interview you can withdraw from the study without having to give a reason.

### **What are the possible benefits of taking part?**

There are no clear benefits for you personally in this research. If you do take part then you will be helping to contribute to our understanding of what it is like to be in hospital and the difficulties or benefits of talking to other people about ideas or beliefs which are very important to you. We hope this will help in the future to find ways of improving responses to people affected by such beliefs.

### **What if something goes wrong?**

We will try to make the interview a comfortable experience for you. Our researchers are trained in this kind of work and will treat any information you share confidentially and with respect. If you have any worries about this research please talk to the researcher. If you feel that doesn't help then you may wish to discuss your concerns with the clinical team or even make a formal complaint through the hospital's complaints procedure.

### **Will my participation in this research be kept confidential?**

All your information will be kept strictly confidential to this research study – this includes everything you tell the researcher and any information from your medical notes. Everything you tell us will remain private and will not be shared with your doctors, nurses, family, visitors or anyone else.

The only exception to this concerns safety. If you said that you intended to harm yourself or someone else in the near future then we would have to share this information (but only this information, nothing else you have told us) with your primary nurse or doctor. In the unlikely event that you choose to tell us about any specific plans you might have to try and leave the hospital without permission, or to do anything else specifically aimed at breaching safety, we would also tell your doctor about this.

If you are happy to take part in the study then we will remove your name and any identifying information from our research records, and give you a research number instead. When we write about the results of our research, it will not be possible to identify you personally from the information published.

### **What will happen to the findings of the research study?**

The results will be written in papers for professional journals, and in reports which will be submitted in order for the researchers to gain postgraduate qualifications. There will also be reports prepared for the people who fund and approve our research. Information about the identity of people who participate in this study will not be included in any of the reports about the findings of the study. If you want to find out more about how to access this information in the future please ask us.

### **Who is organising and funding the research study?**

This research is being organised by psychiatrists, psychologists and other professionals who are employed in the School of Medicine at Cardiff University.

### **Who has reviewed and approved the research study?**

Before beginning this research project, our plans were reviewed by <insert name> Multi-Centre research Ethics Committee who have raised no objection on ethical grounds. This research has also been approved by <Bro Morgannwg NHS Trust / Avon and Wiltshire Mental Health Partnership / Llanarth Court Management Team.>

### **How to get further information**

We will ensure that staff in the hospital know how to contact our researchers. Your nurse or doctor will be able to contact us if they need more information about our work or if you have any questions that we have not already answered. If you want to contact us directly then please write to us:

Forensic Psychiatry Research Group  
Department of Psychological Medicine  
School of Medicine  
Cardiff University  
Heath Park  
Cardiff  
CF14 4XN

**Thank you very much for reading this information sheet.** If you do decide to take part in the research then we will give you a copy of this sheet and the consent form to keep.

## Appendix 8: Consent form for patient participants



### CONSENT FORM

#### A RESEARCH STUDY TO FIND OUT ABOUT IMPORTANT BELIEFS WHICH ARE ATTRIBUTED TO ILLNESS: DO PEOPLE TALK ABOUT THEIR BELIEFS AND WHAT ARE THE EFFECTS OF DOING SO?

Name of Researcher: .....

Please tick each box if you agree to the item

I ☐ have read the information about this research study and have had an opportunity to ask any questions about it.

I ☐ understand that I do not have to take part in this research study and that I am free to withdraw from the study without my medical care or legal rights being affected.

I ☐ give permission for my medical records to be looked at in strict confidence by researchers working on this project.

I ☐ understand that I will not benefit personally from taking part in this research.

☐ I agree to take part in this research study.

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date



## **Appendix 9: The University Graduate College Programme**

<b>Knowledge &amp; Intellectual Abilities</b>	<b>Date</b>
SPSS: An Introduction	11-12/11/2010
Word: Working with Long Documents, Microsoft	18/11/2009
EndNote: An Introduction to Managing your References	20/05/2009
Starting Out: Induction Event for New Researchers	20/01/2009
<hr/>	
<b>Personal Effectiveness</b>	
<hr/>	
Career Planning for Researchers (Biomedical & Life Sciences): Exploring your Options beyond Academia	08/07/2011
Effective CV Writing	24/11/2009
Effective Researcher	15-16/06/2009
Time Management	24/03/2009
<hr/>	
<b>Research Governance &amp; Organisation</b>	
<hr/>	
Practical Project Management for Your Research	08/09/2009
<hr/>	
<b>Engagement Influence &amp; Impact</b>	
<hr/>	
English for Research Writing (for non-native Speakers of English)	27/06/2011
English for Research Writing (for non-native Speakers of English)	20/06/2011
Consultancy Skills for Researchers: An Introduction	15/06/2011
Writing and Publishing Your Research (Biomedical & Life Sciences)	08/06/2011



English for Research Writing (for non-native Speakers of English)	06/06/2011
English for Research Writing (for non-native Speakers of English)	23/05/2011
PowerPoint: Enhancing Your Presentation, Microsoft	25/11/2009
Annual Lecture: Graduate School in Biomedical & Life Sciences	28/10/2009
Presenting Research Orally	05/05/2009
PowerPoint: An Introduction to Creating a Presentation, Microsoft	11/03/2009
Speaking of Science Conference Pre-Event Training Course	26/02/2009
Teaching Skills (Open Programme): Creating an Inclusive	20/02/2009

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### **Research Methods**

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Quantitative & Qualitative Research Methods (part 2)	25/01/2010
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**Appendix 10:** Interview organisation and data collection between researchers

Researcher 1	Researcher 2	Researcher 3	Hospitals 1,2 and 3
PATIENTS	STAFF	RELATIVES	
RELATIVES	PATIENTS	STAFF	

**First interview**

Name of the patient:

Date of the Interview:

Name of the hospital and ward:

**Nominated staff:**

Staff telephone number:

**Nominated relative:**

Relative telephone number:

**Second interview after 4 weeks**

Patient:

Staff:

Relative:

## Appendix 11: The Comprehensive Psychopathology Rating Scale (CPRS)

Sadness  
Elation  
Inner tension  
Hostile feelings  
Inability to feel  
Pessimistic thoughts  
Suicidal thoughts  
Hypochondriasis  
Worrying over trifles  
Compulsive thoughts  
Phobias  
Rituals  
Indecision  
Inertia  
Fatigability  
Concentration difficulties  
Failing memory  
Reduced appetite  
Reduced sleep  
Increased sleep  
Reduced sexual interest  
Increased sexual interest  
Autonomic disturbances  
Aches and pains  
Muscular tension  
Loss of sensation or movement  
Depersonalisation  
Derealisation  
Feeling controlled  
Disrupted thoughts  
Ideas of persecution  
Ideas of grandeur  
Delusional mood  
Ecstatic experiences  
Morbid jealousy  
Other delusions  
Commenting voices  
Other auditory hallucinations  
Visual hallucinations  
Other hallucinations

Apparent sadness  
Elated mood  
Hostility  
Labile emotional responses  
Lack of appropriate emotion  
Autonomic disturbances  
Sleepiness  
Distractibility  
Withdrawal  
Perplexity  
Blank spells  
Disorientation  
Pressure of speech  
Reduced speech  
Specific speech defects  
Flight of ideas  
Incoherent speech  
Perseveration  
Overactivity  
Slowness of movement  
Agitation  
Involuntary movements  
Muscular tension  
Mannerisms and postures  
Hallucinatory behaviour

### **Global rating of illness**

Assumed reliability of rating

Åsberg M, Montgomery SA, Perris D, Schalling D, Sedvall G. (1978). The Comprehensive Psychopathological Rating Scale. *Acta Psychiatrica Scandinavica* 271: 5-27.

### ***Instructions to users***

The rating should be based on a flexible clinical interview where the subject is initially encouraged to describe in his own words, and in as much detail as possible, symptoms that are relevant to him / her. The interviewer should then decide which items in the scale have not been fully covered, and phrase questions in as broad and neutral a manner as possible to allow the subject to elaborate these areas. If this is not sufficient for the rating, more specific questions may be needed. The first interview in a series intended to measure change is to some extent a training session for both the rater and the subject. It may therefore be useful to let the interview cover a much longer time span than will eventually be rated, to make sure that the subject fully understands the questions and to let the rater familiarise himself with the subject's history. This will make it easier for the rater to phrase the pertinent questions in later interviews. We have found it used, and would recommend, that a separate sheet is used for each new rating.

## ***Reported psychopathology***

### 1. Sadness

Representing subjectively experienced mood, regardless of whether it is reflected in appearance or not. Include depressed mood, low spirits, despondency, and the feeling of being beyond help and without hope.

Rate according to intensity, duration and the extent to which the mood is influenced by events. Elated mood is scored zero on this item.

- 0 Occasional sadness may occur in the circumstance.
- 1 Predominant feelings of sadness
- 2 Pervasive feelings of sadness or gloominess. The mood is hardly influenced by external circumstances
- 3 Continuous experience of misery or extreme despondency.

### 2. Elation

Representing subjectively experienced mood, regardless of whether it is reflected in demeanour or not. Includes reports of wellbeing, high spirits, and unvarying exuberance.

Rate according to intensity, duration, and the extent to which mood is influenced by external circumstances.

Distinguish from ecstatic experiences (34).

Depressed mood is scored zero.

- 0 Occasional cheerfulness may occur in circumstance
- 1 Predominating feelings of well-being and high spirits, but lower moods occur
- 2 Pervasive feeling of well-being and high spirits. The mood is hardly influenced by circumstances. Longer periods of abundant good humour
- 3 Unvarying exuberance, supreme well-being, intense exhilaration.

### 3. Inner tension

Representing feelings of ill-defined discomfort, edginess, inner turmoil, total tension mounting to panic, dread and anguish.

Rate according to intensity, frequency, duration and the extent of reassurance called for.

Distinguish from worrying (9) / sadness (1) / muscular tension (25).

- 0 Placid. Only fleeting inner tension.
- 1 Occasional feelings of edginess and ill-defined discomfort.
- 2 Continuous feelings of inner tension, or intermittent panic which the patient can only master with some difficulty.
- 3 Unrelenting dread or anguish. Overwhelming panic.

#### 4. Hostile Feelings

Representing irritability, hostility and aggressive feelings, regardless of whether they are acted or not.

Rate according to intensity, frequency, and the amount of provocation tolerated.

Inability to feel angry is scored zero on this item (cf. inability to feel (5)).

- 0 Not easily irritated
- 1 Touchy and prickly but irritation easily dissipated
- 2 Reacts to provocation with excessive anger or hostility
- 3 Persistent anger, rage or intense hatred which is difficult or impossible to control

#### 5. Inability to feel

Representing the subjective experience of reduced interest in the surroundings, or activities, that normally give pleasure. The ability to react with adequate emotion to circumstances or people is reduced.

Distinguish from inertia (14).

- 0 Normal interest in the surrounding and in other people
- 1 Reduced ability to enjoy usual interests. Reduced ability to feel anger
- 2 Loss of interests in surroundings. Loss of feelings for friends and acquaintances
- 3 The experience of being emotionally paralysed, inability to feel anger or grief, and a complete or even painful failure to feel for close relatives and friends.

#### 6. Pessimistic thought

Representing thoughts of guilt, inferiority, self-reproach, sinfulness, remorse and ruin.

- 0 No pessimistic thoughts
- 1 Fluctuating ideas of failure, self-reproach or self-depreciation
- 2 Persistent self accusations or definite but still rational ideas of guilt or sin. Increasingly pessimistic about the future
- 3 Delusions of ruin, remorse and unredeemable sin. Absurd self accusations.

#### 7. Suicidal Thoughts

Representing the feeling that life is not worth living, that a natural death would be welcome, suicidal thoughts and preparations for suicide.

Suicidal attempts should not in themselves influence the rating.

- 0 Enjoys life or takes it as it comes
- 1 Weary of life. Only fleeting suicidal thoughts.
- 2 Much better off dead. Suicidal thoughts are common and suicide is considered as a possible solution but without specific plans or intentions.
- 3 Explicit plans for suicide when there is an opportunity. Active preparations for suicide.

### 8. Hypochondriasis

Representing exaggerated preoccupations or unrealistic worrying about ill health or disease.

Distinguish from worrying (9) aches and pains (24) and loss of sensation / movement (26)

- 0 No particular preoccupation with ill health
- 1 Reacting to minor bodily dysfunction with foreboding. Exaggerated fear of disease
- 2 Convinced that there is some disease but can be reassured, if only briefly.
- 3 Incapacitating or absurd hypochondriachal convictions (body rotting away, bowels have not worked for months).

### 9. Worrying over trifles

Representing apprehension and undue concern over trifles, which is difficult to stop and out of proportion to the circumstances.

Distinguish from aches and pains (24), loss of sensation (26).

- 0 No particular worries
- 1 Undue concern. Worrying that can be shaken off
- 2 Apprehensive and bothered about trifles or minor routines
- 3 Unrelenting and often painful worrying. Reassurance is ineffective.

### 10. Compulsive thoughts

Representing disturbing or frightening thoughts or doubts which are experienced as silly or irrational, but keep coming back against one's will.

Distinguish from hypochondriasis (8) worrying over trifles (9) or disrupted thoughts (30)

- 0 No repetitive thoughts
- 1 Occasional compulsive thoughts which are not disturbing
- 2 Frequent disturbing compulsive thoughts
- 3 Incapacitating or obnoxious obsessions, occupying one's entire mind.

### 11. Phobias

Representing feelings of unreasonable fear in specific situations (such as buses, supermarkets, crowds, feeling enclosed, being alone) which are avoided if possible.

- 0 No phobias
- 1 Feelings of vague discomfort in particular situations which can be mastered without help or by taking simple precautions like avoiding rush hours where possible
- 2 Certain situations constantly provoke marked discomfort, and are avoided without impairing social performance
- 3 Incapacitating phobias which severely restrict activities: for example: completely unable to leave home

## 12. Rituals

Representing a compulsive repeating of particular acts or rituals which are regarded as unnecessary or absurd and resisted but cannot be suppressed without discomfort.

- 0 No compulsive behaviour
- 1 Slight compulsive behaviour
- 2 Clear-cut rituals which do not interfere with social performance
- 3 Extensive rituals or checking habits that are time consuming and incapacitating

## 13. Indecision

Representing vacillation and difficulty in choosing between simple alternatives. Distinguish from worrying over trifles (9) and compulsive thoughts (10).

- 0 No indecisiveness
- 1 Some vacillation but can still make a decision when necessary
- 2 Indecisiveness or vacillation which restricts or prevents action, makes it difficult to answer simple questions or make simple choices
- 3 Extreme indecisiveness even in situations where conscious deliberation is not normally required, such as whether to sit, enter or stay outside

## 14. Inertia

Representing a difficulty getting started or slowness initiating and performing everyday activities.

Distinguish from indecision (13) and fatigability (15).

- 0 No difficulty getting started, no sluggishness
- 1 Difficulty starting new activities
- 2 Difficulties in starting very routine activities, which are carried out only with effort
- 3 Complete inertia. Unable to start any activity without help

## 15. Fatigability

Representing the experience of tiring more easily than usual. When inertia (14) is extreme this item is difficult to evaluate. If impossible, do not rate.

- 0 Ordinary staying power
- 1 Tires easily but does not have to take a break more often than usual
- 2 Easily wearied. Frequently forced to pause or rest
- 3 Exhaustion interrupts almost all activities or even makes them impossible

## 16. Concentration difficulties

Representing difficulties in collecting one's thoughts, mounting to incapacitating lack of concentration. Rate according to intensity, duration, frequency and degree of incapacitation. Distinguish from failing memory (17) and disrupted thoughts (30).

- 0 No difficulties concentrating
- 1 Occasional difficulties collecting one's thoughts
- 2 Difficulties in concentrating and sustaining thought which interfere with reading or conversation
- 3 Incapacitating lack of concentration



### 17. Failing memory

Representing subjective disturbances of recall compared with previous ability.  
Distinguish from concentration difficulties (16).

- 0 Memory as usual
- 1 Occasional lapses of memory
- 2 Reports of socially inconvenient or disturbing loss of memory
- 3 Complaints of complete inability to remember

### 18. Reduced appetite

Representing the feeling of a loss of appetite compared with when well.

- 0 Normal or increased appetite
- 1 Slightly reduced appetite
- 2 No appetite – Food is tasteless. Needs to force self to eat
- 3 Must be forced to eat. Food refusal

### 19. Reduced sleep

Representing a subjective experience of reduced duration or depth of sleep compared with the subject's own normal pattern when well.

- 0 Sleep as usual
- 1 Slight difficulty dropping off to sleep or slightly reduced. Light or fitful sleep.
- 2 Sleep reduced or broken by at least two hours
- 3 Less than two or three hours' sleep

### 20. Increased sleep

Representing a subjective experience of increased duration or depth of sleep compared with subject's own normal pattern when well.

- 0 No extra sleep
- 1 Sleeps longer or deeper than normal
- 2 Several hours extra sleep
- 3 Spends a great part of the day asleep in spite of normal or increased sleep at night.

### 21. Reduced sexual interest

Representing descriptions of a reduced sexual interest or a reduction of sexual activity (this should always be judged against the subject's usual sexual habits when well). Habitual impotence or frigidity should be ignored when assessing interest.  
Distinguish from inability to feel (5).

Increased sexual interest is rated zero.

- 0 No reduction of sexual interest
- 1 Sexual interest is admitted to be reduced, but activity is unimpaired
- 2 Definite reduction of sexual interest. Ordinary sexual activities are reduced or non-existent
- 3 Complete sexual indifference

## 22. Increased sexual interest

Representing descriptions of a stronger sexual interest than usual, which may be reflected in an increase in sexual activities or fantasies. (This should always be judged against the subject's usual sexual habits when well).

- 0 No increase in sexual interest
- 1 Increase in sexual interest or fantasies not reflected in activities
- 2 Definite increase in sexual interest or activities or intrusive sexual fantasies
- 3 Totally preoccupied with sexual fantasies. Very marked interest in sexual activities.

## 23. Autonomic disturbances

Representing descriptions of palpitations, breathing difficulties, dizziness, increased sweating, cold hands and feet, dry mouth, indigestion, diarrhoea, frequent micturition.

Distinguish from inner tension (3) aches and pains (24) and loss of sensation / movement (26)

- 0 No autonomic disturbances
- 1 Occasional autonomic symptoms which occur under stress
- 2 Frequent or intense autonomic disturbances which are experienced as discomforting or socially inconvenient
- 3 Very frequent autonomic disturbances which interrupt other activities or are incapacitating

## 24. Aches and pains

Representing reports of bodily discomfort, aches and pains.

Rate according to intensity, duration, frequency and request for relief. Disregard any opinion of organic cause.

Distinguish from hypochondriasis (8), autonomic disturbance (23) and muscular tension (25).

- 0 Absent or transient aches
- 1 Occasional definite aches and pains
- 2 Prolonged and inconvenient aches and pains. Request for effective analgesics
- 3 Severely interfering or crippling pains

## 25. Muscular tension

Representing the description of increased tension in the muscles and a difficulty in relaxing physically.

Distinguish from aches and pains (24).

- 0 No increase in muscular tension
- 1 Some occasional increase in muscular tension, more evident in demanding situations
- 2 Considerable difficulty in finding a comfortable position when sitting up. Disturbing muscular tension
- 3 Painful muscular tension. Completely incapable of relaxing physically

## 26. Loss of sensation or movement

Representing impairment or loss of particular motor or sensory functions.

Disregard any organic basis.

Distinguish from hypochondriasis (8), autonomic disturbance (23) and aches and pains (24).

- 0 No impairment of sensory or motor functions
- 1 Slight and transient impairment which does not disturb ordinary activities
- 2 Clear-cut impairment or loss of some function, but manages daily activities without help
- 3 Severely incapacitating and persistent sensory motor loss which necessitates help, such as blindness, inability to walk or speak

## 27. Derealisation

Representing a change in the quality of awareness of the surroundings, which may appear artificial. Also includes déjà-vu, déjà-vecu and changed intensity of perceptions.

Distinguish from depersonalisation (28).

- 0 No change of awareness
- 1 Occasional episodes of déjà vu phenomena or derealisation
- 2 Frequent episodes of derealisation
- 3 Very frequent or persistent derealisation

## 28. Depersonalisation

Representing a change in the quality of awareness of oneself combined with feelings of unreality, bodily change, detachment or radical change of person.

Distinguish from inability to feel (5), derealisation (27) feeling controlled (29).

- 0 No experience of change
- 1 Occasional or vague feelings of change in oneself
- 2 Feelings of change of person which are intrusive
- 3 Continuous experience of a radical and absurd change of one's person

## 29. Feeling controlled

Representing the experience of being, in the literal sense, influenced or controlled from outside, and the experience that feelings, impulses or volitions are imposed from outside. Also rated under the heading is the experience of being able to control others in a similar manner.

Distinguish from disrupted thoughts (30) or ideas of persecution (31)

- 0 Ordinary influence from social forces.
- 1 Vague or unconvincing report of being unnaturally influenced or controlled from without and the experience that feelings, impulses or volitions are imposed from without.
- 2 Occasional but clear experiences of being controlled from without eg. By hypnosis.
- 3 Continuous experiences that feelings or impulses do not derive from one, say by means of rays.

### 30. Disrupted thoughts

Representing the experience of a sudden stoppage of thoughts (thought blocking) or thoughts being put into one's head (insertion) or being taken out (withdrawal) or listened to or broadcast.

Distinguish from compulsive thoughts (10) or concentration difficulties (16)

- 0 No thought interruptions
- 1 Vague or unconvincing reports of episodes of interruptions to thought
- 2 Occasional but clear thought blocking or occasional episodes of thought insertion or withdrawal. Feeling that thoughts are being read.
- 3 Disturbing or disabling thought interruptions. Thought broadcasting.

### 31. Ideas of persecution

Representing suspiciousness, exaggerated self-consciousness, the conviction of being talked about or watched or persecuted with malicious intent.

- 0 No undue suspiciousness or self-consciousness
- 1 Vague feelings of being observed
- 2 Pervasive feelings of being talked about, threatened or persecuted
- 3 Unalterable conviction of being the victim of systematic persecution. Delusional misinterpretation of ordinary events of "cues". Conviction of being referred to beyond the realm of likelihood (for example on television or in newspapers)

### 32. Ideas of grandeur

Representing exaggerated opinion of self importance, capabilities or good health.

Distinguish from elated mood (2) and ecstatic experiences (34).

- 0 No ideas of grandeur
- 1 Self assured, with an inflated sense of one's own importance
- 2 Clearly exaggerated opinion of self importance and capabilities. Grandiose, facile, and completely unrealistic plans for the future
- 3 Absurd, delusional ideas of grandeur.

### 33. Delusional mood

Representing strong, unreasonable premonitions, the feeling or sudden conviction that trivial events or things have a profound and bizarre significance.

Distinguish from derealisation (27) or ecstatic experiences (34)

- 0 Only ordinary superstitions. No delusional mood
- 1 Vague premonitions that something personal and unknown is about to happen
- 2 A strong feeling that generally trivial events have a special significance
- 3 The sudden unshakeable conviction, appearing out of the blue, that a particular set of events has a profound and often bizarre meaning.

### 34. Ecstatic experiences

Representing experiences of mystic rapture, bliss or ecstatic happiness which may involve sudden illumination, insight into religious matters, or union with God.

Distinguish from elation (2) and ideas of grandeur (32).

- 0 No ecstatic experiences
- 1 Occasional and inexplicable feelings of happiness with metaphysical overtones
- 2 Frequent experiences of bliss or rapture connected with feelings of sudden insight into metaphysical matters

### 35. Morbid jealousy

Representing an absorbing preoccupation with the possible unfaithfulness of a sexual partner.

- 0 No undue suspicions towards partner
- 1 Vague feelings of insecurity and suspicions about the partner's faithfulness
- 2 Searches for and misinterprets "evidence" of unfaithfulness
- 3 Morbid ideas of jealousy dominate life and actions. Threatens the partner and tries to extract "confessions".

### 36. Other delusions

Representing any other delusions than those above.

Distinguish from pessimistic thoughts (6), hypochondriasis (8), feeling controlled (29), ideas of persecution (31), ideas of grandeur (32), delusional mood (33) and morbid jealousy (35).

- 0 No other delusions
- 1 Vague and unconvincing descriptions
- 2 Definitely pathological ideas, approaching delusional strength
- 3 Absurd delusions which may be reflected in behaviour

### 37. Commenting voices

Representing the experience of hearing one's own thoughts spoken or repeated aloud, or hearing voices commenting or arguing about one in the third person.

Distinguish from other auditory hallucinations (38).

- 0 No hallucinated commenting voices
- 1 Vague or unconvincing reports of commenting voices
- 2 Definite but not disabling hallucinated voices
- 3 Frequent disabling hallucinated voices

### 38. Other auditory hallucinations

Representing all hallucinated sounds or voices except commenting voices (37). Also includes auditory hallucinations in keeping with predominant mood such as depression or elation.

- 0 No auditory hallucinations, except for on going to sleep
- 1 Misinterpretations of auditory stimuli. Vague or unconvincing reports of auditory hallucination
- 2 Definite hallucinations which may be persistent but not intrusive
- 3 Loud or unpleasant hallucinations. Forceful commands.

### 39. Visual hallucinations

Representing a misinterpretation of a visual stimulus (illusion) or a false visual perception without any actual outside stimulus (hallucination).

No false visual experiences, except for on falling asleep

Occasional illusions

Frequent illusions or occasional visual hallucination

Clear frequent or persistent hallucinations

#### 40. Other hallucinations

Representing hallucinations of taste, smell or bodily sensation. Specify the sense and base the rating on the most severe.

- 0 No hallucinations
- 1 Vague or unconvincing reports of hallucinations
- 2 Occasional but definite hallucination
- 3 Clear, frequent or persistent hallucinations

## ***Observed psychopathology***

### 41. Apparent sadness

Representing despondency, gloom and despair (more than just ordinary transient low spirits) reflected in speech, facial expression and posture. Rate by depth and inability to brighten up.

- 0 No sadness
- 1 Looks dispirited but brightens up occasionally
- 2 Appears sad and unhappy all of the time
- 3 Extreme and continuous gloom and despondency

### 42. Elated mood

Representing an elated and exuberant state (excludes ordinary transient high spirits). Includes evident increased well-being, self-confidence, elation and hilarity shown in speech, choice of subject, facial expression, posture and activity. Rate according to intensity and inability to respond seriously when demanded.

- 0 Normal cheerfulness.
- 1 Self-confident and somewhat expansive, but can change to seriousness when demanded.
- 2 Expansive hilarity with exaggerated self-confidence and mirth that is out of tune. Unable to respond seriously.
- 3 Displays persistent extreme exuberance, exhilaration and absurd hilarity.

### 43. Hostility

Representing irritability, angry looks, words or actions. Rate by intensity and frequency, and the small amount of provocation that elicits the response and time taken to quieten.

- 0 No evident hostility.
- 1 Querulous, touchy and irritable on provocation. Occasional angry glances.
- 2 Pugnacious, quarrelsome, very aggressive gestures, but can be calmed down.
- 3 Threatening behaviour or actual physical violence.

### 44. Labile emotional responses

Representing rapidly changing moods, say to sudden elation or sadness with a tendency to display intense emotional responses. Should not be confused with the preponderant mood. Rate by speed and frequency of change.

- 0 No sudden mood changes.
- 1 Occasional and understandable rapid mood changes.
- 2 Frequent sudden or exaggerated mood changes.
- 3 Very rapid changes between intense opposite moods.

### 45. Lack of appropriate emotion

Representing blunting of affect as shown by lack of emotional expression or the occurrence of incongruous emotional displays which are clearly out of keeping with the situation. Distinguish from apparent sadness (41) and elated mood (42).

- 0 Appropriate affect in keeping with mood.
- 1 Apparent lack of concern, slightly odd displays of emotion.
- 2 Responds in a clearly inappropriate way on sensitive issues, or appears not to respond at all.
- 3 Only clearly bizarre emotional response, or total emotional indifference.

#### 46. Autonomic disturbances

Representing signs of autonomic dysfunction, hyperventilation or frequent sighing, blushing, sweating, cold hands, enlarged pupils and dry mouth, fainting.

- 0 No observed autonomic disturbances.
- 1 Occasional or slight autonomic disturbances such as blushing or blanching, or sweating under stress.
- 2 Obvious autonomic disturbances on several occasions, even when not under stress.
- 3 Autonomic disturbances which disturb the interview.

#### 47. Sleepiness

Representing evident diminished ability to stay awake as seen in facial expression, speech, or posture. Distinguish from withdrawal (49), perplexity (50) and slowness of movement (60).

- 0 Fully awake.
- 1 Looks sleepy, yawns occasionally.
- 2 Tends to fall asleep when left in peace.
- 3 Falls asleep during interview or is difficult to wake.

#### 48. Distractibility

Representing attention easily diverted by irrelevant external stimuli. Distinguish from withdrawal (49), perplexity (50), blank spells (51), flight of ideas (56), hallucinatory behaviour (65).

- 0 Adequately sustained attention.
- 1 Attention occasionally distracted by irrelevant stimuli (such as background noises).
- 2 Easily distracted.
- 3 Continually distracted by incidental events and objects, which makes interviewing difficult or impossible.

#### 49. Withdrawal

Representing grossly restricted attention and apparent unawareness of people or surroundings. Distinguish from sleepiness (47), perplexity (50), blank spells (51), reduced speech (54).

- 0 Apparently well aware of the surroundings.
- 1 Occasional withdrawal, but attention can be brought back without difficulty.
- 2 Appears absent and withdrawn and is only brought back to the interview with difficulty.
- 3 Completely withdrawn. Appears not to react to words or touch.



#### 50. Perplexity

Representing bewilderment, a difficulty in comprehending any situation and interpreting the context. Distinguish from sleepiness (47), distractibility (48) and withdrawal (49).

- 0 No perplexity.
- 1 Puzzled. Occasional difficulty understanding what should be simple questions.
- 2 Appears bewildered. Simple questions must be repeated to be understood. Occasional answers unrelated to the question.
- 3 Obviously perplexed and bewildered. Speech and behaviour inappropriate, as if in a dream.

#### 51. Blank spells

Representing sudden stoppages and inattention while speaking, which last for a few seconds or longer. It is often accompanied by immobility and apparent thought blocking. Distinguish from reduced speech (54), specific speech defects (55) and incoherent speech (57).

- 0 No blank spells.
- 1 Occasional lapses which could be interpreted as a wandering of the mind.
- 2 Obvious blank spells even when not under particular stress.
- 3 Frequent or long blank spells which interfere with conversation.

#### 52. Disorientation

Representing failure of orientation in time and place.

- 0 Fully oriented.
- 1 Minimal disorientation as to day or date.
- 2 Marked disorientation for date some disorientation in time.
- 3 Markedly disoriented for time and place.

#### 53. Pressure of speech

Representing pressure to talk, increased flow of speech and undue loquaciousness. Reduced speech is scored zero on this item. Distinguish from flight of ideas (56) and incoherent speech (57).

- 0 Ordinary speech without undue loquaciousness
- 1 Rapid verbose speech. Gives detailed answers.
- 2 Garrulous and difficult to interrupt.
- 3 Leads the interview. Words come tumbling out. Cannot be interrupted.

#### 54. Reduced speech

Representing reticent or slowed speech with long delays or pauses. Pressure of speech is scored zero on this item. Distinguish from withdrawal (49), perplexity (50) blank spells (51) specific speech defects (55).

- 0 Ordinary speech without undue pauses.
- 1 Takes time to produce brief answers.
- 2 Extremely brief monosyllabic answers with long delays. Hardly any spontaneous comments and when they occur they are slow.
- 3 Monosyllabic answers are only produced with great effort. Almost or completely mute.

### 55. Specific speech defects

Representing for example stuttering, dysarthria and aphasia – specify the type and any obvious reason.

- 0 No specific difficulties with speech.
- 1 Occasional speech deficits, especially when upset.
- 2 Very evident speech defects which are intrusive but do not interfere with communication.
- 3 Persistent and disturbing speech defects which markedly interfere with communication.

### 56. Flight of ideas

Representing a rapid flow of ideas shown in speech. There is a continuity of thought, even if it is difficult or even impossible to catch up, in contrast to incoherent speech (57).

- 0 Ordinary flow of ideas.
- 1 Free and lively associations with a tendency to drift in the discussion.
- 2 Rapid flow of ideas which can be followed. Frequent changes of subject which interferes with conversation.
- 3 The rapid changes of subject and the richness and speed of associations make conversations extremely difficult or impossible.

### 57. Incoherent speech

Representing circumlocutory, disorganised or apparently illogical speech with inexplicable shifts from topic to topic, distortion and fragmentation of syntax and words.

Distinguish from flight of ideas (56).

- 0 Coherent and understandable speech.
- 1 Pedantic and slightly circumlocutory speech. Some idiosyncratic but comprehensive use of words or phrases, especially under stress.
- 2 Illogical association between words or phrases, even when not under stress. “Knights move” shifts.
- 3 Obviously disjointed and illogical speech; fragmentation.

### 58. Perseveration

Representing a tendency to get stuck, to repeat sentences or actions such as repeating the answer to a previous question to subsequent questions and to return constantly to the same topic, or being unable to interrupt a thought or action.

- 0 No perseveration.
- 1 The same phrase is occasionally repeated. Returns to the same question several times.
- 2 Repeats the same phrase, but can be persuaded to give more adequate answers. Difficulties in interrupting a line of thought or an action once started.
- 3 Perseverating phrases or behaviour makes communication difficult or impossible.

### 59. Overactivity

Representing an increase in frequency and extent of voluntary movement (facial movement, gait, accompanying movements and gestures) and an increased speed in their initiation and completion.

Distinguish from agitation (61) and involuntary movements (62).

- 0 Ordinary change between activity and rest.
- 1 Lively gestures and hurried gait but can rest.
- 2 Obviously expansive and rapid movements and gestures. Abrupt reactions. Leaves the chair occasionally during the interview.
- 3 Continuous wildly exaggerated motor activity. Cannot be persuaded to sit or lie down.

#### 60. Slowness of movement

Representing a decrease in frequency and extent of voluntary movements. Facial movements, gait, accompanying movements and gestures retarded and sluggish.

- 0 Ordinary changes between rest and activity.
- 1 Minimal gestures and facial movements.
- 2 Almost no spontaneous motor activity. Slow and laboured movement.
- 3 Has to be led to the interview. No spontaneous movements. Immobile face. Stupor.

#### 61. Agitation.

Representing “purposeless” motor activity such as hand-wringing, picking at objects and clothes, inability to sit still.

Distinguish from overactivity (59), involuntary movements (62) and mannerisms (64).

- 0 No agitation.
- 1 Difficult to keep hands still. Changes position several times during the interview. Fiddles with objects.
- 2 Obviously restless. Vacant and obtrusive picking at objects. Half rises occasionally.
- 3 Cannot be persuaded to sit except for brief periods. Incessant purposeless wandering.

#### 62. Involuntary movements

Representing the following involuntary movements – tics, tremors, choreo-athetotic movements, dyskineasias, dystonias, and torticollis. Specify the type.

- 0 No involuntary movements.
- 1 Occasional involuntary movements when under stress.
- 2 Obvious and frequent involuntary movements, accentuated when under stress. Manages not to let them interfere with ordinary motor activity.
- 3 Continuous involuntary movements which seriously interfere with ordinary activities.

#### 63. Muscular tension

Representing observed muscular tension as shown in facial expression, posture and movements.

- 0 Appears relaxed.
- 1 Slightly tense face and posture.
- 2 Moderately tense posture and face (easily seen in jaw and neck muscles). Does not seem to find a relaxed position when sitting. Stiff and awkward movements.
- 3 Strikingly tense. Often sits hunched and crouched, or tense and rigidly upright at the edge of the chair.

#### 64. Mannerisms and postures

Representing repeated or stereotypical complex movements or postures, such as grimacing, stylised movements, odd postures, catalepsy. The rating is based on frequency and degree of interference with other activities.

Distinguish from perseveration (58), agitation (61) and involuntary movements (62), especially tics.

- 0 No mannerisms.
- 1 Occasional or doubtful grimaces or stylised movement.
- 2 Mannerisms, grimaces or postures which are obvious but which do not interfere.
- 3 Pronounced mannerism or postures which take over from ordinary motor activity.

#### 65. Hallucinatory behaviour

Representing odd behaviour suggestive of hallucinations, for example, turning around suddenly, shouting or apparently answering voices, retracting from presumed visual hallucinations. Should be rated regardless of whether hallucinations are admitted or not. Distinguish from involuntary movements (62) and mannerisms and posturing (64).

- 0 No hallucinatory behaviour.
- 1 Odd behaviour like talking to oneself which might represent hallucinatory behaviour but is thought not to.
- 2 Convincing hallucinatory behaviour.
- 3 Bizarre or frequent hallucinatory behaviour which interferes with the interview.

#### 66. Global rating of illness

- 0 None. Absence of illness.
- 1 Minimal or doubtful illness which does not interfere.
- 2 Moderate or definite illness.
- 3 Severe or incapacitating illness.

#### 67. Assumed reliability of the rating

- 0 Very poor
- 1 Fair
- 2 Good
- 3 Very good

**Appendix 12: The Maudsley Assessment of Delusions Schedule (MADS)-Patient's version**

**MAUDSLEY ASSESSMENT OF DELUSIONS SCHEDULE-2 Patient's version (MADS-2P)**

*An extended version of:* THE MAUDSLEY ASSESSMENT OF DELUSIONS SCHEDULE

Pamela J Taylor, Phillipa Garety, Alec Buchanan, Alison Reed, Simon Wessely, Katarzyna Ray, Graham Dunn & Don Grubin (1994) Delusions and violence. In J. Monahan and H.J. Steadman (Eds) *Mental Disorder and Violence. Developments in risk assessment*. Chicago University Press: Chicago 161-182.

This interview is designed to follow on immediately from a general mental state examination, generally the CPRS.

As far as possible, the CPRS will be conducted asking about symptoms in the order listed until arriving at the psychotic symptoms. Ideally the questions which refer to delusions should be reserved until last. The interview can then more naturally move to the MADS. If, however, the delusions are so pre-occupying that the person appears to need to talk about them at the beginning and it seems more natural to do that, then the interviewer should complete all the interviewing about the delusions at this stage and record doing so and why.

Content of delusions should be fully drawn out and recorded as part of the CPRS.

If only one delusion is referred to, then the MADS is conducted with respect to that delusion.

If there is more than one delusion, the interviewee should then be asked: **of [all] the beliefs we have just talked about, which do you think is the most important?**

The MADS is going to be about that belief.

Experience has suggested that people with a psychotic illness rarely have difficulty in choosing a belief. For those who do a written list noted in response to the earlier question might be presented to the patient to assist choice. If the patient still fails to choose the most important belief then the interviewer may select the belief most strongly held; if this fails the belief selected should be that indicated by staff as the most consistently reported.

**If it is necessary to go through any part or all of this process, record the process**

The sequence of questions is indicated in the MADS. Although possible for the sequence of questions to be changed, experience has shown that questions relating to violent and antisocial behaviour and the patient's insight into the consequences seem best placed at the end of the questionnaire so as least likely to compromise rapport with the individual.

All of the questions in bold should be asked; the wording may be changed to suit linguistic and cultural background of the interviewee. It should be changed where necessary so that the question specifically relates to the belief chosen for evaluation. NB. It may be helpful to gain from the casenotes some preliminary impression of the likely delusion in order to prepare particularly for Q 2.6

Subsidiary questions are discretionary. Ratings should be made as indicated in the text. For some items the instruction 'specify' appears. In these instances a verbatim account of the patient's answer should be recorded. For optimal ratings the interview, unless otherwise stated in an individual item, should explicitly address the four weeks prior to interview. Accuracy of recall is likely to decrease if the time is extended and practical usefulness if it reduced.

RESEARCH CODE .....  
INTERVIEW NUMBER .....

**DESCRIPTIVE NOTE OF PRINCIPAL BELIEF** (use patient's verbatim account where possible)

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**1. CONVICTION**

**1.01 How sure are you about X?**

**Do you have any doubts at all?**

Absolutely certain	4
Almost certain	3
Quite certain	2
Have some doubts	1
Definitely doubt it	0

**1.02 Now, I want to focus particularly on the last month, but before I do, can I ask you how long X has been true for you?**

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**2. BELIEF MAINTENANCE**

**Can you now explain why you continue to think that X is so? Has anything happened in the last month to confirm your belief since the idea first came to you?**

Item 2.01 – 2.07 to be rated 0 = No 1 = Yes 9 = Don't know

Prompt if necessary: anything happening in your surroundings? In your every day life?

**2.01 External events?** 9 1 0

note nature of event(s) – list if necessary, and any relevant details

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**2.02 Internal state maintaining belief** (e.g. mood, abnormal experience; all relevant hallucinations should be regarded as internal states even if the patient perceives their focus to be external). 9 1 0

Prompt if necessary: anything in you? Anything changing in you?

Note nature of state and all relevant details .....

.....

**2.03 Do you at present (or have you in the past month) looked for any evidence or information either to confirm your view or to test whether it may be mistaken?** 9 1 0

**2.04 Asking you to think about it now – can you think of anything at all that has happened that goes against your beliefs?** 9 1 0

**2.05 When you think about it now is it at all possible that you might be mistaken about X?** 9 1 0  
(‘maybe’ should be rated as ‘yes’)

**2.06 Let me suggest something hypothetical to you – something that does not fit with your view and let me ask you tell me how you think you would react.**

The details of the question will have to be made up in the context of the delusion under study. Both question and response should be recorded.

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.....

Ignores or rejects relevance = 4  
Accommodates into system = 3  
Increases conviction = 2  
Decreases conviction = 1  
Dismisses belief = 0

### 3. AFFECT RELATING TO CHOSEN BELIEF

Rate only for emotional variance which is alleged to be *specifically consequent on* the belief.

Does it make you feel:	Yes	No
<b>3.01 Elated?</b>	1	0
<b>3.02 Unhappy / miserable / depressed?</b>	1	0
<b>3.03 Terrified / frightened?</b>	1	0
<b>3.04 Anxious / tense?</b>	1	0

### 3.05 Angry?

1

0

## 4. ACTION ON BELIEFS

### Does X make you do anything in particular?

Record spontaneous account of the nature of the acts.

.....

.....

.....

Now I want you to focus again particularly on the last month  
Rate all items on the following basis:

Did not occur	= 0
'Sometimes' or 'occasionally' (once / wk or less)	= 1
'Often' (more than once / wk)	= 2
Not applicable, not known	= 9

#### Definite 'positive' acts

4.01 Have you told anyone about X?	9	2	1	0
------------------------------------	---	---	---	---

4.02 Have you written to anyone?	9	2	1	0
----------------------------------	---	---	---	---

4.03 Have you tried to stop X from happening?	9	2	1	0
---	---	---	---	---

4.04 Have you tried to protect yourself in any way?	9	2	1	0
---	---	---	---	---

(Specify .....

.....)

4.05 Does X make you lose your temper?	9	2	1	0
--	---	---	---	---

4.06 Have you broken anything because of this?	9	2	1	0
--	---	---	---	---

4.07 Have you felt like hitting someone because of it?	9	2	1	0
--	---	---	---	---

4.08 Have you hit anyone because of it?	9	2	1	0
---	---	---	---	---

4.09 Do you know the person/people you have/may have harm(ed)?	9	2	1	0
--	---	---	---	---

(Specify relationship .....

.....)

4.10 Have you tried to harm yourself or harmed yourself accidentally because of X?	9	2	1	0
--	---	---	---	---

(Specify .....

.....)



<b>4.11 Have you tried to move or leave your house (area) because of X?</b>	9	2	1	0
---	---	---	---	---

<b>4.12 Have other changes resulted?</b>	9	2	1	0
--	---	---	---	---

(Specify .....)

.....)

**ONLY FOR THOSE HEARING VOICES:**

<b>4.13 Do the voice(s) tell you to do anything?</b>	9	2	1	0
--	---	---	---	---

<b>4.14 Do you have to obey?</b>	9	2	1	0
----------------------------------	---	---	---	---

<b>4.15 Do you do anything to escape them?</b>	9	2	1	0
--	---	---	---	---

<b>4.16 Do the voices have any relationship to X?</b>	9	2	1	0
---	---	---	---	---

4.17. Tell me a bit about how they relate

.....

.....

.....

4.18 Can you remember if the voices were there before X?

**NEGATIVE BEHAVIOURS**

**Has X stopped you from doing things you would normally have done?**

<b>4.16 Has X stopped you from meeting friends?</b>	9	2	1	0
---	---	---	---	---

<b>4.17 Has X stopped you from watching T.V. or listening to the radio?</b>	9	2	1	0
---	---	---	---	---

<b>4.18 Has X stopped you from eating/drinking anything?</b>	9	2	1	0
--	---	---	---	---

<b>4.19 Has X stopped you from using transport?</b>	9	2	1	0
---	---	---	---	---

<b>4.20 Has X stopped you from going to work?</b>	9	2	1	0
---	---	---	---	---

<b>4.21 Has X stopped you from taking medication?</b>	9	2	1	0
---	---	---	---	---

<b>4.22 Has X stopped you from going to your hospital/ your doctor on an outpatient basis?</b>	9	2	1	0
--	---	---	---	---

<b>4.23 Is there anything else which X has stopped you from doing? (record verbatim and code)</b>	9	2	1	0
---	---	---	---	---

.....

.....

## 5. IDIOSYNCRASY OF BELIEF

### 5.01 How far do you think others share your beliefs?

Completely	4
To a considerable extent	3
To some extent	2
Hardly at all	1
Not at all	0

### 5.02 Do you ever have arguments about your beliefs?

Frequently (most days)	4
Quite often (at least once/wk)	3
Sometimes (at least once/mth)	2
Once or twice ever	1
Never	0

## 5.1 COMMUNICATION ABOUT BELIEF

### 5.11. Do you speak about X with other people?

Yes	1
No	0

If no, move to item 6

If yes, ask the following:

### 5.12. Can you please give me an estimate of how often that happens

Frequently (most days)	4
Quite often (at least once/wk)	3
Sometimes (at least once/mth)	2
Once or twice ever	1
Never	0

### 5.13. Please give me some idea of who you might talk with about X (list all; add prompts systematically, where necessary: anyone in your family? Any of your friends? Someone from the health services? Someone else? [If none reported even after prompting: There's really no-one?])

.....

.....

.....

.....

### 5.14 Who do you feel you can really confide in/talk to most easily about X?

(Prompts should enable choice of one member of the patient's chosen social circle and one professional person. e.g. but who is really the most easy to talk with? Or if two given: can I press you to say which one of them is really the easiest to talk with/you would really want to talk to if you had completely free choice; if the individual is stuck for choice between more than two, be prepared to put the names on a piece of paper and get the patient to pile them up in order of importance with the easiest/most important person to talk to on the top. If it is still impossible to force a choice, then choose one of these names at random.)

Relationship to nominated person (1) from social circle .....

Relationship to nominated professional person (2) .....

5.15 How often in the last month have you talked to (1) about X?

Frequently (most days)	4
Quite often (at least once/wk)	3
Sometimes (at least once/mth)	2
Once or twice ever	1
Never	0

If never, clarify when they last did speak to (1) about X .....

5.16 How often in the last month have you talked to (2) about X?

Frequently (most days)	4
Quite often (at least once/wk)	3
Sometimes (at least once/mth)	2
Once or twice ever	1
Never	0

If never, clarify when they last did speak to (2) about X .....

**5.17.01 Please think back to the last conversation you had with (1) about X.**

Please can you tell me what you told (1) about it

.....

.....

.....

5.17.02 What did they say to this?

.....

.....

.....

5.17.03 Did that affect how you thought about X? 0 1

5.17.04 If yes, how?

.....

.....

5.17.05 Did what they said affect how you felt? 0 1

5.17.06 If yes, how?

.....

.....

5.17.07 Did what they said affect anything that you did? 0 1

5.17.08 If yes, how?

.....  
.....

5.17.09 Did it affect anything else? 0 1  
5.17.10 If yes, how?

.....  
.....

5.17.11 Researcher's overall estimate of whether the conversation had any effect on the nature or quality of the belief

Ignores or rejects relevance = 4  
Accommodates into system = 3  
Increases conviction = 2  
Decreases conviction = 1  
Dismisses belief = 0

Observations .....  
.....  
.....

5.17.12 Researcher's overall estimate of whether the conversation had any effect on the affect of the patient

Rate each affect: made worse 2 made better 1, no effect 0, not applicable 8

- 5.17.12.1 Elated?  
5.17.12.2 Unhappy / miserable / depressed?  
5.17.12.3 Terrified / frightened?  
5.17.12.4 Anxious / tense?  
5.17.12.5 Angry?

\_\_\_\_\_

*Please can we now think in the same way about how you talk with (2) about X*

5.18.01 Please think back to the last conversation you had with (2) about X. Please can you tell me what you told (1) about it

.....  
.....  
.....

5.18.02 What did they say to this?

.....  
.....  
.....

5.18.03 Did that affect how you thought about X? 0 1

5.18.04 If yes, how?

.....  
.....

5.18.05 Did what they said affect how you felt? 0 1

5.18.06 If yes, how?

.....  
.....

5.18.07 Did what they said affect anything that you did? 0 1

5.18.08 If yes, how?

.....  
.....

5.18.09 Did it affect anything else? 0 1

5.18.10 If yes, how?

.....  
.....

5.18.11 Researcher's overall estimate of whether the conversation had any effect on the nature or quality of the belief

Ignores or rejects relevance = 4  
 Accommodates into system = 3  
 Increases conviction = 2  
 Decreases conviction = 1  
 Dismisses belief = 0

Observations .....  
.....  
.....

5.18.12 Researcher's overall estimate of whether the conversation had any effect on the affect of the patient

Rate each affect: made worse 2 made better 1, no effect 0, not applicable 8

5.18.12.1 Elated?

5.18.12.2 Unhappy / miserable / depressed?

5.18.12.3 Terrified / frightened?

5.18.12.4 Anxious / tense?

5.18.12.5 Angry?

## 6. PREOCCUPATION WITH CHOSEN BELIEFS

NB It may not be necessary to ask specific questions about this here, but the interviewer should rate preoccupation at the time of the interview, not attempt to estimate preoccupation retrospectively, e.g. at the time any act was committed.

6.01	4	3	2	1	0	
None						= 0
Thinks sometimes of past delusions only						= 1
Current delusion definitely present but can turn attention to other things						= 2
Current delusion takes up most of time. Preoccupied to the exclusion of many other matters.						= 3
Patient can hardly discuss anything but delusion.						= 4

## 7. SYSTEMATISATION OF CHOSEN BELIEF

NB It may not be necessary to ask specific questions about this here, but the interviewer should rate systematisation at the time of the interview, not attempt to estimate preoccupation retrospectively, e.g. at the time any act was committed.

7.01	3	2	1	0	
None					= 0
Delusions not elaborated into general system					= 1
Some systematic elaboration but substantial areas of experiences not affected					= 2
Interprets practically all experiences in delusion terms.					= 3

## 8. INSIGHT

8.01 Uniqueness

***Earlier I asked you about whether or not you felt others shared your belief about X. I'd like to clarify whether you feel that other people also believe X – either openly or perhaps without talking about it.***

Accepts uniqueness of belief	= 0
Accepts that others do not openly share belief	= 1
Says the belief is shared by many others	= 2

8.02 Evidence

***What would have to happen to make you think that you might be wrong about X?***

Able to outline evidence and accept this outcome to be logically possible	= 0
Able to outline evidence but not accept this outcome logically possible	= 1
Unable to outline evidence which would contradict belief	= 2

8.03 Treatment (1)

***Do you think that seeing a psychiatrist might help you (has helped you) in any way?***

Accepts need to see a psychiatrist (regardless of reason)	= 0
No need to see a psychiatrist but will see one if asked	= 1
No need to see a psychiatrist and will only see one under duress	= 2

(To score '0' or '1' on this question or on item 8.04 the reasons given for wanting psychiatric help need not relate to the delusional belief)

8.04 Treatment (2)

***Do you think that medication might help you (has helped you) in any way? ... How?***

Accepts need for drug treatment (regardless of reason)	= 0
No need for drug treatment but has/will accept it when offered	= 1
Refusing to accept medication	= 2
No drug prescribed	= 9

8.05 Self-protection

***How much have you discussed X with your doctor and the nurses on the ward?***

Refuses to discuss beliefs	= 0
Discusses beliefs only under direct questioning	= 1
Eager to discuss beliefs with all	= 2

8.06 Illness

***Are you psychologically unwell in any way...is there anything wrong with your nerves?***

Accepts that has a mental illness or nervous problem which includes delusional belief	= 0
Accepts that has a mental illness or nervous problem but does not include delusional belief	= 1
Not ill; belief sound	= 2

**SECTIONS 8.07 – 8.10 ONLY TO BE RATED FOR THOSE SUBJECTS WHO HAVE ACTED VIOLENTLY OR DANGEROUSLY ON THEIR DELUSION**

Specify the action under consideration

.....  
.....

8.07 Moral

***Looking back on (the behaviour X), do you now feel that you were justified, or were you wrong to do what you did?***

Accepts that behaviour or act was wrong, and feels remorse	= 0
Accepts that behaviour or act was wrong, but feels justified	= 1
Denies behaviour or act was wrong	= 2
Not applicable	= 9

8.08 Legal

***Was (the behaviour X) against the law?***

Accepts illegality and now believes that should not have broken the law	= 0
Accepts illegality but feels justified in breaking the law	= 1
Does not consider the law to be relevant / denies illegality	= 2
Not applicable	= 9

8.09 Risk

***How dangerous was (the behaviour X) ... would you take the same risk again?***

Recognises risk, and now feels the risk was not worth it	= 0
Recognises risk, but feels risk was worth it	= 1
Risk irrelevant, or does recognise any risk	= 2
Not applicable	= 9

8.10 Reaction of others

***Why do you feel that (the people involved) responded to you in the way they did – were they right?***

Understands the reactions of others and accepts these are reasonable	= 0
Accepts the reactions of others but cannot agree with them	= 1
Cannot understand why others reacted to behaviour as they did	= 2
Not applicable	= 9



**Appendix 13:** Demographic, clinical and historical data completed from case notes/electronic database

1. ID
2. DOB
3. Gender
4. Ethnicity
5. Marital status
6. Occupation
7. Hospital
8. Living Status
9. DOCA (Date of current admission)
10. DOD (Date of Discharge)
11. Diagnosis
12. Offending history reported by staff)
13. History of Violence
14. History of Suicide/Parasuicide
15. Legal Status
16. Psychiatric History (More/Less than 3 years)
17. Compulsory admission
18. On Psychotropic Medication
19. History of Substance abuse

**Appendix 14:** The Maudsley Assessment of Delusions Schedule (MADS) - Informant's version

## **The MAUDSLEY ASSESSMENT OF DELUSIONS SCHEDULE- Participant's Version (MADS-R)**

*An extended version of:* **THE MAUDSLEY ASSESSMENT OF DELUSIONS SCHEDULE**

Pamela J Taylor, Phillipa Garety, Alec Buchanan, Alison Reed, Simon Wessely, Katarzyna Ray, Graham Dunn & Don Grubin (1994) Delusions and violence. In J. Monahan and H.J. Steadman (Eds) *Mental Disorder and Violence. Developments in risk assessment*. Chicago University Press: Chicago 161-182.

This interview is designed to follow on immediately from a general mental state examination, generally the CPRS. As far as possible, the CPRS will be conducted asking about symptoms in the order listed until arriving at the psychotic symptoms. Ideally the questions which refer to delusions should be reserved until last. The interview can then more naturally move to the MADS. If, however, the delusions are so pre-occupying that the person appears to need to talk about them at the beginning and it seems more natural to do that, then the interviewer should complete all the interviewing about the delusions at this stage and record doing so and why. Content of delusions should be fully drawn out and recorded as part of the CPRS. If only one delusion is referred to, then the MADS is conducted with respect to that delusion.

If there is more than one delusion, the interviewee should then be asked: **of [all] the beliefs we have just talked about, which do you think is the most important?**

The MADS is going to be about that belief.

Experience has suggested that people with a psychotic illness rarely have difficulty in choosing a belief. For those who do a written list noted in response to the earlier question might be presented to the patient to assist choice. If the patient still fails to choose the most important belief then the interviewer may select the belief most strongly held; if this fails the belief selected should be that indicated by staff as the most consistently reported.

**If it is necessary to go through any part or all of this process, record the process**

The sequence of questions is indicated in the MADS. Although possible for the sequence of questions to be changed, experience has shown that questions relating to violent and antisocial behaviour and the patient's insight into the consequences seem best placed at the end of the questionnaire so as least likely to compromise rapport with the individual.

All of the questions in bold should be asked; the wording may be changed to suit linguistic and cultural background of the interviewee. It should be changed where necessary so that the question specifically relates to the belief chosen for evaluation. NB. It may be helpful to gain from the case notes some preliminary impression of the likely delusion in order to prepare particularly for Q 2.6

Subsidiary questions are discretionary. Ratings should be made as indicated in the text. For some items the instruction 'specify' appears. In these instances a verbatim account of the patient's answer should be recorded. For optimal ratings the interview, unless otherwise stated in an individual item, should explicitly address the four weeks prior to interview. Accuracy of recall is likely to decrease if the time is extended and practical usefulness if it reduced.

RESEARCH CODE .....  
INTERVIEW NUMBER .....

**DESCRIPTIVE NOTE OF PRINCIPAL BELIEF** (use informant's verbatim account where possible)

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**1. CONVICTION**

**1.01 How sure do you think is (s/he) about X?**

**Does (s/he) have any doubts at all?**

Absolutely certain	4
Almost certain	3
Quite certain	2
Have some doubts	1
Definitely doubt it	0

**1.02 Now, I want to focus particularly on the last month, but before I do, can I ask you how long X has been true for (s/he)?**

---

---

**2. BELIEF MAINTENANCE**

**Can you now explain why (s/he) continue to think that X is so? Has anything happened in the last month to confirm (s/he)s' belief since the idea first came to her/him?**

Item 2.01 – 2.07 to be rated 0 = No 1 = Yes 9 = Don't know

Prompt if necessary: anything happening in your surroundings? In your every day life?

**2.01 External events?** 9 1 0

Note nature of event(s) – list if necessary, and any relevant details

---

.....

**2.02 Internal state maintaining belief** (e.g. mood, abnormal experience; all relevant hallucinations should be regarded as internal states even if the patient perceives their focus to be external). 9 1 0

Prompt if necessary: anything in (her/him)? Anything changing in (her/him)?

Note nature of state and all relevant details .....

.....

**2.03 Does (s/he) at present (or have (s/he) in the past month month) looked for any evidence or information either to confirm her/his view or to test whether it may be mistaken?** 9 1 0

**2.04 Can you think of anything at all that could have happened that goes against (s/he) beliefs?** 9 1 0

**2.05 Do you ever think is it at all possible that (s/he) might be right about X?** 9 1 0  
('maybe' should be rated as 'yes')

### 3. AFFECT RELATING TO CHOSEN BELIEF

Rate only for emotional variance which is alleged to be *specifically consequent on* the belief.

Do you think X makes (s/he) feel:	Yes	No
<b>3.01 Elated?</b>	1	0
<b>3.02 Unhappy / miserable / depressed?</b>	1	0
<b>3.03 Terrified / frightened?</b>	1	0
<b>3.04 Anxious / tense?</b>	1	0
<b>3.05 Angry?</b>	1	0

### 4. ACTION ON BELIEFS

**Does X make (s/he) do anything in particular?**  
Record spontaneous account of the nature of the acts.

.....

.....

.....

Now I want you to focus again particularly on the last month  
Rate all items on the following basis:

Did not occur	= 0
'Sometimes' or 'occasionally' (once / wk or less)	= 1
'Often' (more than once / wk)	= 2
Not applicable, not known	= 9

Definite 'positive' acts

<b>4.01 Has (s/he) told anyone about X?</b>	9	2	1	0
---	---	---	---	---

<b>4.02 Has (s/he) written to anyone?</b>	9	2	1	0
---	---	---	---	---

<b>4.03 Has (s/he) tried to stop X from happening?</b>	9	2	1	0
--	---	---	---	---

<b>4.04 Has (s/he) tried to protect her/him self in any way?</b>	9	2	1	0
--	---	---	---	---

(Specify .....)

.....)

<b>4.05 Does X make (s/he) lose her/his temper?</b>	9	2	1	0
---	---	---	---	---

<b>4.06 Has (s/he) broken anything because of this?</b>	9	2	1	0
---	---	---	---	---

<b>4.07 Has (s/he) felt like hitting someone because of it?</b>	9	2	1	0
---	---	---	---	---

<b>4.08 Has (s/he) hit anyone because of it?</b>	9	2	1	0
--	---	---	---	---

<b>4.09 Do you know the person/people (s/he) have/may have harm(ed)?</b>	9	2	1	0
--	---	---	---	---

(Specify relationship .....)

.....)

<b>4.10 Has (s/he) tried to harm her/himself or harmed her/himself accidentally because of X?</b>	9	2	1	0
---	---	---	---	---

(Specify .....)

.....)

<b>4.11 Has (s/he) tried to move or leave her/his house (area) because of X?</b>	9	2	1	0
--	---	---	---	---

<b>4.12 Have other changes resulted?</b>	9	2	1	0
--	---	---	---	---

(Specify .....)

.....)

## NEGATIVE BEHAVIOURS

**Has X stopped (s/he) from doing things (s/he) would normally have done?**

<b>4.13 Has X stopped her/him from meeting friends?</b>	9	2	1	0
<b>4.14 Has X stopped her/him from watching T.V. or listening to the radio?</b>	9	2	1	0
<b>4.15 Has X stopped her/him from eating/drinking anything?</b>	9	2	1	0
<b>4.16 Has X stopped her/him from using transport?</b>	9	2	1	0
<b>4.17 Has X stopped her/him from going to work?</b>	9	2	1	0
<b>4.18 Has X stopped her/him from taking medication?</b>	9	2	1	0
<b>4.19 Has X stopped her/him from going to her/his hospital/ her/his doctor on an outpatient basis?</b>	9	2	1	0
<b>4.20 Is there anything else which X has stopped (s/he) from doing? (record verbatim and code)</b>	9	2	1	0

.....

.....

## ONLY FOR THOSE HEARING VOICES:

**Does (s/he) hear voice(s)?**

Yes	1
No	0

If no, move to item 4.16

If yes, ask the following:

<b>4.21 Do the voice(s) tell (her/him) to do anything?</b>	9	2	1	0
<b>4.22 Does (s/he) have to obey?</b>	9	2	1	0
<b>4.23 Does (s/he) do anything to escape them?</b>	9	2	1	0
<b>4.24 Do the voices have any relationship to X?</b>	9	2	1	0

4.25. Can you tell me a bit about how they relate?

.....

.....

.....

4.26 Can you remember if the voices of (s/he) were there before X ?

## 5. IDIOSYNCRASY OF BELIEF

### 5.01 Do you think that (s/he) believe that others share her/his beliefs?

Completely	4
To a considerable extent	3
To some extent	2
Hardly at all	1
Not at all	0

### 5.02 Does (s/he) ever have arguments about her/his beliefs?

Frequently (most days)	4
Quite often (at least once/wk)	3
Sometimes (at least once/mth)	2
Once or twice ever	1
Never	0

## 5.1 COMMUNICATION ABOUT BELIEF

### 5.11. Does (s/he) speak about X with other people?

Yes	1
No	0

If no, move to item 6

If yes, ask the following:

### 5.12. Can you please give me an estimate of how often that happens?

Frequently (most days)	4
Quite often (at least once/wk)	3
Sometimes (at least once/mth)	2
Once or twice ever	1
Never	0

5.14. Please give me some idea of whom (s/he) might talk with about X (list all; add prompts systematically, where necessary: anyone in your family? Any of your friends? Someone from the health services? Someone else? [If none reported even after prompting: There's really no-one?])

.....  
.....  
.....  
.....

5.15 Who do you think that (s/he) can really confide in/talk to most easily about X?  
(Prompts should enable choice of one member of the patient's chosen social circle and one professional person. e.g. but who is really the most easy to talk with? Or if two given: can I press you to say which one of them is really the easiest to talk with/you would really want to talk to if you had completely free choice; if the individual is stuck for choice between more than two, be prepared to put the names on a piece of paper and get the patient to pile them up in order of importance with the easiest/most important person to talk to on the top. If it is still impossible to force a choice, then choose one of these names at random.)

Relationship to nominated person (1) from social circle .....

Relationship to nominated professional person (2) .....

5.15 How often in the last month have (s/he) talked to (1) about X?

Frequently (most days)	4
Quite often (at least once/wk)	3
Sometimes (at least once/mth)	2
Once or twice ever	1
Never	0

If never, clarify when they last did speak to (1) about X .....

5.16 How often in the last month has (s/he) talked to (2) about X?

Frequently (most days)	4
Quite often (at least once/wk)	3
Sometimes (at least once/mth)	2
Once or twice ever	1
Never	0

If never, clarify when they last did speak to (2) about X .....

*5.17.01 Please think back to the last conversation (s/he) had with you about X. Can you please tell me what (s/he) told you about it*

.....  
.....  
.....

5.17.02 What did you say to this?

.....  
.....  
.....

5.17.03 Did that affect how (s/he) thought about X? 0 1

5.17.04 If yes, how?

.....  
.....

5.17.05 Did what you said affect how (s/he) felt? 0 1

5.17.06 If yes, how?

.....  
.....

5.17.07 Did what you said affect anything that (s/he) did? 0 1



5.17.08 If yes, how?

.....  
.....

5.17.09 Did it affect anything else? 0 1

5.17.10 If yes, how?

.....  
.....

5.17.13 Researcher's overall estimate of whether the conversation had any effect on the nature or quality of the belief

Ignores or rejects relevance = 4  
Accommodates into system = 3  
Increases conviction = 2  
Decreases conviction = 1  
Dismisses belief = 0

Observations .....  
.....  
.....

5.17.14 Researcher's overall estimate of whether the conversation had any effect on the affect of the informant.

Rate each affect: made worse 2 made better 1, no effect 0, not applicable 8

5.17.12.1 Elated?

5.17.12.2 Unhappy / miserable / depressed?

5.17.12.3 Terrified / frightened?

5.17.12.6 Anxious / tense?

5.17.12.7 Angry?

## 6. PREOCCUPATION WITH CHOSEN BELIEFS

NB It may not be necessary to ask specific questions about this here, but the interviewer should rate preoccupation at the time of the interview, not attempt to estimate preoccupation retrospectively, e.g. at the time any act was committed.

6.01 4 3 2 1 0

None = 0  
Thinks sometimes of past delusions only = 1  
Current delusion definitely present but can turn attention to other things = 2  
Current delusion takes up most of time. Preoccupied to the exclusion of many other matters. = 3  
Patient can hardly discuss anything but delusion. = 4

## 7. SYSTEMATISATION OF CHOSEN BELIEF

NB It may not be necessary to ask specific questions about this here, but the interviewer should rate systematisation at the time of the interview, not attempt to estimate preoccupation retrospectively, e.g. at the time any act was committed.

7.01	3	2	1	0	
None					= 0
Delusions not elaborated into general system					= 1
Some systematic elaboration but substantial areas of experiences not affected					= 2
Interprets practically all experiences in delusion terms.					= 3

## 8. INSIGHT

### 8.01 Uniqueness

***Earlier I asked you about whether or not (s/he) felt others shared her/his belief about X. I'd like to clarify whether (s/he) feels that other people also believe X – either openly or perhaps without talking about it.***

Accepts uniqueness of belief	= 0
Accepts that others do not openly share belief	= 1
Says the belief is shared by many others	= 2

### 8.02 Evidence

***What would have to happen to make (s/he) think that (s/he) might be wrong about X?***

Able to outline evidence and accept this outcome to be logically possible	= 0
Able to outline evidence but not accept this outcome logically possible	= 1
Unable to outline evidence which would contradict belief	= 2

### 8.03 Treatment (1)

***Do you feel that (s/he) think seeing a psychiatrist might help her/him (has helped her/him) in any way?***

Accepts need to see a psychiatrist (regardless of reason)	= 0
No need to see a psychiatrist but will see one if asked	= 1
No need to see a psychiatrist and will only see one under duress	= 2

(To score '0' or '1' on this question or on item 8.04 the reasons given for wanting psychiatric help need not relate to the delusional belief)

### 8.04 Treatment (2)

***Do you feel that (s/he) think that medication might help her/him (has helped her/him) in any way? ... How?***

Accepts need for drug treatment (regardless of reason)	= 0
No need for drug treatment but has/will accept it when offered	= 1
Refusing to accept medication	= 2
No drug prescribed	= 9

#### 8.05 Self-protection

***How much have (s/he) discussed X with her/his doctor and the nurses on the ward?***

Refuses to discuss beliefs	= 0
Discusses beliefs only under direct questioning	= 1
Eager to discuss beliefs with all	= 2
I do not know	= 9

#### 8.06 Illness

***Is (s/he) psychologically unwell in any way...is there anything wrong with her/his nerves?***

Accepts that has a mental illness or nervous problem which includes delusional belief	= 0
Accepts that has a mental illness or nervous problem but does not include delusional belief	= 1
Not ill; belief sound	= 2

#### **SECTIONS 8.07 – 8.10 ONLY TO BE RATED FOR THOSE SUBJECTS WHO HAVE ACTED VIOLENTLY OR DANGEROUSLY ON THEIR DELUSION**

Specify the action under consideration

.....  
.....

#### 8.07 Moral

***Looking back on (the behaviour X), do (s/he) now feel that (s/he) were justified, or were (s/he) wrong to do what (s/he) did?***

Accepts that behaviour or act was wrong, and feels remorse	= 0
Accepts that behaviour or act was wrong, but feels justified	= 1
Denies behaviour or act was wrong	= 2
Not applicable	= 9

#### 8.08 Legal

***Was (the behaviour X) against the law?***

Accepts illegality and now believes that should not have broken the law	= 0
Accepts illegality but feels justified in breaking the law	= 1
Does not consider the law to be relevant / denies illegality	= 2
Not applicable	= 9

#### 8.09 Risk

***How dangerous was (the behaviour X) ... would (s/he) take the same risk again?***

Recognises risk, and now feels the risk was not worth it	= 0
Recognises risk, but feels risk was worth it	= 1
Risk irrelevant, or does recognise any risk	= 2
Not applicable	= 9

#### 8.10 Reaction of others

***Why do you feel that (the people involved) responded to (s/he) in the way they did – were they right?***

Understands the reactions of others and accepts these are reasonable	= 0
Accepts the reactions of others but cannot agree with them	= 1
Cannot understand why others reacted to behaviour as they did	= 2
Not applicable	= 9

## **Appendix 15: The Maudsley Assessment of Delusions Schedule (MADS) - The informant interview**

"We are interested to know whether X behaved in ways that seemed to you either odd, unusual, disturbing or in any way out of the ordinary during the month prior to admission. We are interested in what X actually did, as well as the possible reasons for it."

### **Behaviour in the home**

- 1.1 Has anything s/he heard on television, radio or in the newspapers, during the past month, seemed to give rise to any odd or unusual behaviour or distress? If so, can you give me an example? How often has that sort of thing occurred? What do you think was the reason for the behaviour?
- 1.2 Has X been writing letters or making telephone calls to unusual people?
- 1.3 Has X been feeling unsafe, frightened or scared at home? If so, has X been taking extra precautions, such as locking the door or putting a chain on the door?
- 1.4 Has there been any change in X's eating or drinking habits? Has s/he been refusing food or drink?
- 1.5 Has X been dressing in an unusual, inappropriate or different way?
- 1.6 Has X been behaving in the house in any other different or unusual way?

### **Behaviour to others**

- 2.1 Has X been suspicious of people recently? If so, how has this been shown? Has X been checking on anyone, or jealous of anyone?

### **Violent behaviour (against people)**

*Do not rate violent threats*

- 3.1 Has X been violent to anyone? Who? In what way was s/he violent? Did s/he use a weapon? Was there any injury?

### **Antisocial behaviour (against property inside or outside the home)**

- 4.1 Has X damaged anything, either inside or outside the home? What has been damaged?
- 4.2 Has X been doing anything else likely to get him/her into trouble?

### **Behaviour to self**

- 5.1 Has X tried to harm him/herself?

### **Behaviour outside the home**

- 6.1 Has X contacted the police? Has X contacted anyone else in authority, such as lawyers, MPs?
- 6.2 Has X been worried about his/her health? Has s/he visited a doctor or the hospital?
- 6.3 Has X attended any new meetings or joined any new organisations?
- 6.4 Has X been spending money in an extravagant or unusual way? If so, what on?

### **Behaviour at work**

7.1 Has X been working during the last month? Do you know if X behaved in any new, unusual or odd ways while at work?

### **Religious behaviour**

8.1 Does X have any strong religious views? Has s/he attended church recently? Has X developed any new religious beliefs? Has s/he done anything because of these beliefs?

### **Others**

9.1 Has X done anything else unusual, odd or new in the last month that you haven't already mentioned?

Any positive answers should be probed further, and a full description of the behaviour, its frequency and any possible motives obtained. Frequency should be rated as follows:

0 = did not occur

1 = one of these behaviours definitely occurred on at least one occasion, but no evidence of anything but rare

2 = occurred more than once but not frequently (e.g. not more than five times)

3 = occurred frequently (e.g. at least five times)

4 = present more or less continuously (at least every day).

**Taken from Wessely, Buchanan, Reed et al. (1993) Acting on delusions. I: Prevalence. *British Journal of Psychiatry*, 163, 69-76.**

## Appendix 16: Example of verbatim transcriptions of staff FMSS

Patient's name	Staff verbatim
X	<p>X is a very pleasant lady who's 40 something. She's been married for over 20 years and she's got two children, very grown up. X's the kind of person who does struggle with life events. She also struggles with any kind of changes that occur in her life. X's always been looked after by her husband, she used to have a job but since she became mentally unwell, it's kind of subsided, and her husband's taken on a carer's role. X is not very independent; she's very reliant on others to do things for her. She's got quite a lot of barriers up that take a lot to get to know her. X isn't very easy to get to know. She's so surrounded by her delusional beliefs that sometimes it takes a long, long time to break those barriers down and get through them.</p> <p>X can be very abrupt, and people mistake this for rudeness, but personally I think its to do with the fact that she's got so many delusions going on that people cant understand that she struggles to speak around these, and how she actually is. X's got no concept of her premorbid personality and has no insight into her mental health problems. X's also very difficult to get to know because her delusions are so prominent you're not sure what is true and what is false in what she says.</p> <p>Whenever you have one-to-one interactions with X she's more interested in going off topic onto what she wanted to talk about rather than the important things. And whenever she reads her care plan she very rarely agrees with them, because she believes that they're all lies and that her husband has orchestrated all of this against her.</p> <p>It's quite difficult to spend time with X because she doesn't stick to topic. She also finds that its quite difficult to engage with staff. Gaye during one-to-one interactions can tend to be easily distracted.</p> <p>X has more interest in talking about her own personal opinions rather than listening to staff. X also doesn't like to acknowledge certain things that are going on such as her delusional beliefs about staff she refuses to, to even listen to what people have to say in terms of this. X is also very hard to deal with in that she's not very happy with mediational changes or regimes. She seems to have an idealised version of her old consultant, and this does impact on how much she trusts her new consultant, Dr L. He placed her on a medication Paroxetine that doesn't agree with her, yet she continues to use it, rather than listen to her new consultants opinion and go on to clozapine.</p> <p>X also has preoccupations with side effects of medication and can be almost psychosomatic in that she'll develop these side effects regardless of any physical evidence of whether she's got them or not. Gaye can also take to her bed quite easily, she's quite difficult to wake up in the morning. She blames it on the medication even though some of the medication she's on isn't sedating. The medication she's on that is sedating is given at teatime on the 6 o'clock dose so that she isn't over</p>

	<p>sedated, yet she claims to have it.</p> <p>X is an irrational lady as well, even though some of her fantasies, delusions and beliefs don't have any continuity to them, she'll be adamant that what she knows is true and that what she believes is correct.</p> <p>Even when staff have attempted to say to her that some things don't fit together or add up, X will find a way for them to add up. X also is preoccupied with the computer and the internet and typing various names and places, and this just adds to her anxiety. X has got a lot of anxiety, due to the fact that she can't rationalise, and then when she can't rationalise her anxiety and agitation increases and it's a circle, and then she'll take to her bed again and claiming she's all sedated because she can't deal with what's going on inside her head.</p> <p>X is currently on clozapine and refuses to increase the dose even though the dose she's on doesn't seem to be having that much of an effect on her. She doesn't understand the difficulties her family goes through and she can be quite difficult to engage with family around because she thinks that she's got a lover waiting for her outside the relationship and doesn't want to jeopardise that.</p> <p>I do appreciate with X that she does always come to staff, even if you can't rationalise what she's thinking. X will always, you know, let you know about her thoughts and beliefs. It doesn't matter if you believe her or not, it doesn't matter how much you question her, she will always come back to you and let you know what's happening inside her head. X is a good patient on the ward because she does talk to staff, she doesn't rely on required medication, she tends to try and deal with things herself.</p> <p>She hasn't recently started CBT which she finds beneficial, and staff have found that it's helped her to be a bit more rational. Even though she's adamant that her thoughts and beliefs are correct, she can see that staff might disagree with them as a matter of process of opinion anyway.</p> <p>X finds it difficult to deal with everyday life. She doesn't like to do the daily routine things that she used to do at home. She doesn't like shopping, cooking and cleaning. She does prefer following her husband round in taxis because part of her delusional belief is that her husband is having copious affairs.</p> <p>She will pay various amounts of money to follow her husband around to prove these affairs. She also has quite intrusive thoughts in that she thinks people's body languages are telling her that her husband is having an affair.</p> <p>She thinks people's body languages and hair colour on people convey what kind of person her husband is having an affair with. She does also have a fixation that one staff nurse on the ward is an ex-partner of hers. And when you actually speak to her he was never actually a partner, he was just somebody that she fell in lust with at the school gates and she can't rationalise that it didn't happen and it's not happening now.</p>
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**Appendix 17:** Characteristics of patients, with details of whether and who they nominated as people they spoke to about their delusions

<b>PATIENT CHARACTERISTICS</b>	<b>Patient did not nominate n (%)</b>	<b>Staff only nominated n (%)</b>	<b>Relative only nominated n (%)</b>	<b>Both Relative &amp; Staff nominated n= (%)</b>	<b>Total patients n (%)</b>	<b>Difference between groups P value</b>
<b>GENDER</b> M F	5 (19) 6 (60)	7 (27) 2 (20)	2 (8) 1 (10)	12 (46) 1 (10)	26 (72) 10 (28)	P=0.81 FET=0.07
<b>OCCUPATIONAL STATUS</b> Unemployed Employed	9 (41) 1 (10)	5 (23) 3 (30)	3 (14) 0 (0)	5 (23) 6 (60)	22 (69) 10 (31)	P=0.20 FET=0.10
<b>MARITAL STATUS</b> Single Living with partner/Married Divorced/Separated/Widowed	5 (25) 2 (40) 4 (50)	7 (35) 0 (0) 1 (12.5)	1 (5) 2 (40) 0 (0)	7 (35) 1 (20) 3 (37.5)	20 (61) 5 (15) 8 (24)	P=0.18 FET=0.21
<b>LIVING STATUS</b> Alone With family members/friends	7 (35) 4 (33)	4 (20) 3 (25)	2 (10) 1 (8)	7 (35) 4 (33)	20 (62.5) 12 (37.5)	P=0.98 FET= 1
<b>HISTORY OF VIOLENCE</b> Absent Present	5 (33) 4 (25)	4 (27) 4 (25)	1 (7) 2 (12.5)	5 (33) 6 (37.5)	15 (48) 16 (52)	P=0.91 FET= 1
<b>OFFENDING HISTORY</b> Absent Present	5 (31) 3 (21)	4 (25) 3 (21)	1 (6) 2 (14)	6 (37.5) 6 (43)	16 (48.5) 14 (42)	P=0.28 FET=0.47
<b>PSYCHIATRIC DIAGNOSIS</b> Schizophrenia Schizoaffective disorder Bipolar disorder Other	3 (14) 2 (100) 4 (11) 2 (6)	7 (33) 0 (0) 1 (12.5) 1 (3)	2 (9.5) 0 (0) 1 (12.5) 0 (0)	9 (43) 0 (0) 2 (25) 2 (6)	21 (58) 2 (6) 8 (22) 5 (14)	P=0.36 FET=0.39
<b>HOSPITAL TYPE</b> General Forensic	10 (42) 1 (8)	5 (21) 4 (33)	3 (12.5) 0 (0)	6 (25) 7 (58)	24 (67) 12 (33)	P=0.61 FET=0.07

**Appendix 18:** Difference in nominations between those with a diagnosis of schizophrenia and patients with any other psychosis

PSYCHIATRIC DIAGNOSIS	No nomination n (%)	Any nomination (SO/ Staff/Both) n (%)	Total patients in diagnosis n (%)	Statistics
Schizophrenia	3 (14)	18 (86)	21 (58)	FET=0.025
Other diagnoses	8 (53)	7 (47)	15 (42)	

**Appendix 19:** Characteristics of all patients according to depression subscale-CPRS and their ability to nominate

<b>CPRS Depression subscale</b>	<b>No nomination n (%)</b>	<b>Any nomination (SO/ Staff/Both) n (%)</b>	<b>Total patients n (%)</b>	<b>Statistics</b>
<b>Reported sadness</b> Present Absent	4 (33) 7 (29)	8 (66) 17 (70)	12 (33) 24 (67)	p=0.54
<b>Apparent sadness</b> Present Absent	3 (30) 8 (31)	7 (70) 18 (69)	10 (28) 26 (72)	p= 0.64
<b>Fatigability</b> Present Absent	4 (25) 7 (35)	12 (75) 13 (65)	16 (44) 20 (56)	p= 0.39
<b>Inner tension</b> Present Absent	3 (38) 8 (29)	5 (62) 20 (71)	8 (22) 28 (78)	p=0.46
<b>Inability to feel</b> Present Absent	4 (25) 7 (25)	4 (50) 21 (58)	8 (22) 28 (78)	p=0.17
<b>Concentration difficulties</b> Present Absent	6 (37) 5 (25)	10 (63) 15 (75)	16 (44) 20 (56)	p=0.32
<b>Reduced sleep</b> Present Absent	3 (27) 8 (32)	8 (73) 17 (68)	11 (31) 25 (69)	p= 0.55
<b>Reduced appetite</b> Present Absent	1 (33) 10 (30)	2 (67) 23 (70)	3 (8) 33 (92)	p= 0.67
<b>Pessimistic thoughts</b> Present Absent	3 (25) 8 (33)	9 (75) 16 (67)	12 (33) 24 (67)	p=0.45
<b>Suicidal thoughts</b> Present Absent	2 (20) 9 (35)	8 (80) 17 (65)	10 (28) 26 (72)	p=0.33

**Appendix 20:** Number of symptoms according to CPRS (depression subscale) and their ability to nominate

CPRS (Depression subscale)		No nomination n (%)	Any nomination n (%)	Total n (%)	Statistic
Number of symptoms	0	1 (14.4%)	6 (16.7%)	7 (19.4%)	FET=0.31
	1	4 (50%)	4 (50%)	8 (22.2%)	
	2	2 (40%)	3 (60%)	5 (13.9%)	
	3	0 (0.0%)	3 (100.0%)	3 (8.3 %)	
	4	0 (0%)	2 (100%)	2 (5.6)	
	5	0 (0.0%)	2 (100.0%)	2 (5.6%)	
	6	1 (100%)	0 (0%)	1 (2.8%)	
	7	0 (0.0%)	3 (100.0%)	3 (8.3%)	
	9	1 (100.0%)	0 (0.0%)	1 (2.8%)	
	10	0 (0.0%)	1 (100.0%)	1 (2.8%)	
<b>Total</b>		<b>11 (30.6%)</b>	<b>25 (69.4%)</b>	<b>36 (100.0%)</b>	

**Appendix 21:** Number of psychotic symptoms (CPRS) reported by the patients and ability to nominate

CPRS (Psychotic subscale)		No nomination n (%)	Any nomination n (%)	Total n (%)	Statistic
Number of symptoms	0	1 (50)	1 (50)	2 (6)	FET=0.61
	1	1 (14)	6(86)	7 (19)	
	2	1 (20)	4 (80)	5 (13.9)	
	3	2(25)	6 (75)	8 (22 )	
	4	3 (60)	2 (40)	5 (14)	
	5	3 (43)	4 (57)	7 (19)	
	6	0 (0)	2 (100)	2 (6 )	
Total		11 (31)	25 (69)	36 (100.0)	

**Appendix 22:** Difference in negative (terrified, angry or sad) affective impact reported and ability to nominate

Negative affect accompanying delusion	No nomination n (%)	Any nomination (SO/ Staff/Both) n (%)	Total patients in diagnosis n (%)	Statistics
Present	9 (33)	18 (67)	27 (75)	FET=0.69
Absent	2 (22)	7 (79)	15 (25)	

**Appendix 23:** Patients ability to nominate someone according to violence relating to their delusion

<b>Violence accompanying delusion</b>	<b>No nomination n (%)</b>	<b>Any nomination (SO/ Staff/Both) n (%)</b>	<b>Total n (%)</b>	<b>Statistic</b>
<b>Losing temper</b>				
Present	4 (21)	15 (79)	17 (54)	p=0.28 FET=0.24
Absent	6 (37.5)	10 (62.5)	16 (46)	
<b>Breaking things</b>				
Present	4 (36)	7 (64)	11 (31)	p=0.49 FET=0.38
Absent	6 (25)	18 (75)	24 (69)	
<b>Feeling of hitting someone</b>				
Present	5 (28)	13 (72)	18 (53)	p=0.82 FET=0.56
Absent	5 (31)	11 (69)	16 (47)	
<b>Hitting someone</b>				
Present	1 (12.5)	7 (87.5)	8 (23.5)	p=0.23 FET=0.23
Absent	9 (35)	17 (65)	26 (76.5)	

**Appendix 24:** Patients ability to nominate someone according to violence reported by nursing staff

Violence reported by staff nurse	No nomination n (%)	Any nomination (SO/ Staff/Both) n (%)	Total n (%)	Statistic
Absent	5 (33)	10 (67)	15 (48)	p=0.60 FET=0.45
Present	4 (25)	12 (75)	16 (52)	



**Appendix 25:** The ability of patients to nominate someone according to their delusion content

Type of delusion (content)	No nomination n (%)	Any nomination (SO/ Staff/Both) n (%)	Total n (%)	Statistic
Persecutory	6 (33)	12 (67)	18 (50)	p= 0.57 FET=0.78
Religious	2 (25)	6 (75)	8 (22)	
Grandiose	2 (33)	4 (67)	6 (17)	
Erotomantic	0 (0)	2 (100)	2 (6)	
Hypochondriacal	1 (100)	0(0)	1 (3)	
Morbid Jealousy	0 (0)	1 (100)	1 (3)	
TOTAL	11 (31)	25 (69)	36 (100)	

**Appendix 26:** The MADS – Preliminary coding of items for informants' comparison table

**The MAUDSLEY ASSESSMENT OF DELUSIONS SCHEDULE-2**

**Items for informants' comparison table**

**DESCRIPTIVE NOTE OF PRINCIPAL BELIEF:**

Translate into content as indicated on sheet

**1. CONVICTION**

**1.01 How sure are you about X?**

**Do you have any doubts at all?**

Absolutely /almost certain	1
Quite certain/Have some doubts/Definitely doubt it	0

**2. BELIEF MAINTENANCE**

**Can you now explain why you continue to think that X is so? Has anything happened in the last month to confirm your belief since the idea first came to you?**

Item 2.01 – 2.07 to be rated 0 = No 1 = Yes 9 = Don't know

Prompt if necessary: anything happening in your surroundings? In your everyday life?

<b>2.01 External events?</b>	9	1	0
------------------------------	---	---	---

note nature of event(s) – list if necessary, and any relevant details

.....

.....

<b>2.02 Internal state maintaining belief</b> (e.g. mood, abnormal experience; all relevant hallucinations should be regarded as internal states even if the patient perceives their focus to be external).	9	1	0
---	---	---	---

Prompt if necessary: anything in you? Anything changing in you?

Note nature of state and all relevant details .....

.....

**2.03 Do you at present (or have you in the past month month) looked for any evidence or information either to confirm your view or to test whether it may be mistaken?** 9 1 0

**2.06 Let me suggest something hypothetical to you – something that does not fit with your view and let me ask you tell me how you think you would react.**

The details of the question will have to be made up in the context of the delusion under study. Both question and response should be recorded.

Not sure whether this will be susceptible to comparison if so include, if not omit

Ignores or rejects relevance 2  
Accommodates into system/ increases conviction 1  
Decreases conviction/Dismisses belief 0

### 3. AFFECT RELATING TO CHOSEN BELIEF

Rate only for emotional variance which is alleged to be *specifically consequent on* the belief.

Does it make you feel:	Yes	No
<b>3.01 Elated?</b>	1	0
<b>3.02 Unhappy / miserable / depressed?</b>	1	0
<b>3.03 Terrified / frightened?</b>	1	0
<b>3.04 Anxious / tense?</b>	1	0
<b>3.05 Angry?</b>	1	0

### 4. ACTION ON BELIEFS

**Does X make you do anything in particular?**

Did not occur 0  
'Sometimes'/'occasionally'/'Often' (more than once / wk) 1  
Not applicable, not known 9

Definite 'positive' acts

<b>4.01 Have you told anyone about X?</b>	9	1	0
<b>4.02 Have you written to anyone?</b>	9	1	0
<b>4.03 Have you tried to stop X from happening?</b>	9	1	0
<b>4.04 Have you tried to protect yourself in any way?</b>	9	1	0

(Specify .....  
.....)

<b>4.05 Does X make you lose your temper?</b>	9	1	0
<b>4.06 Have you broken anything because of this?</b>	9	1	0
<b>4.07 Have you felt like hitting someone because of it?</b>	9	1	0
<b>4.08 Have you hit anyone because of it?</b>	9	1	0
<b>4.09 Do you know the person/people you have/may have harm(ed)?</b>	9	1	0

(Specify relationship .....  
.....)

<b>4.10 Have you tried to harm yourself or harmed yourself accidentally because of X?</b>	9	1	0
---	---	---	---

(Specify .....  
.....)

<b>4.11 Have you tried to move or leave your house (area) because of X?</b>	9	1	0
<b>4.12 Have other changes resulted?</b>	9	1	0

(Specify .....  
.....)

#### **ONLY FOR THOSE HEARING VOICES:**

<b>4.13 Do the voice(s) tell you to do anything?</b>	9	1	0
<b>4.14 Do you have to obey?</b>	9	1	0
<b>4.15 Do you do anything to escape them?</b>	9	1	0
<b>4.16 Do the voices have any relationship to X?</b>	9	1	0
<b>4.19 Were the voices were there before X?</b>	9	1	0

#### **NEGATIVE BEHAVIOURS**

**Has X stopped you from doing things you would normally have done?**

<b>4.16 Has X stopped you from meeting friends?</b>	9	1	0
<b>4.17 Has X stopped you from watching T.V. or listening to the radio?</b>	9	1	0

4.18 Has X stopped you from eating/drinking anything?	9	1	0
4.19 Has X stopped you from using transport?	9	1	0
4.20 Has X stopped you from going to work?	9	1	0
4.21 Has X stopped you from taking medication?	9	1	0
4.22 Has X stopped you from going to your hospital/ your doctor on an outpatient basis?	9	1	0
4.23 Is there anything else which X has stopped you from doing? (record verbatim and code)	9	1	0

.....

.....

## 5. IDIOSYNCRASY OF BELIEF

### 5.01 How far do you think others share your beliefs?

Completely/to a considerable extent/to some extent 0  
Hardly at all/not at all 1

### 5.02 Do you ever have arguments about your beliefs?

Frequently (most days)/quite often (at least once/wk)/sometimes (at least once/mth) 1  
Once or twice ever/ never 0

## 5.1 COMMUNICATION ABOUT BELIEF

### 5.11. Do you speak about X with other people?

Yes 1  
No 0

If no, move to item 6

If yes, ask the following:

### 5.12. Can you please give me an estimate of how often that happens

Frequently (most days)/ quite often (at least once/wk) 2  
Sometimes (at least once/mth)/once or twice ever 1  
Never 0

5.15. Please give me some idea of who you might talk with about X (list all; add prompts systematically, where necessary: anyone in your family? Any of your friends? Someone from the health services? Someone else? [If none reported even after prompting: There's really no-one?])

Derive a suitable coding for who the patient talks to e.g. Parent  
Other relative  
Friend

primary nurse  
other nurse  
other staff (specify)

and for relative when applicable, and staff:

5.15 How often in the last month have you talked to (1) about X? (Adjust coding as above)

Frequently (most days)	4
Quite often (at least once/wk)	3
Sometimes (at least once/mth)	2
Once or twice ever	1
Never	0

5.17.01 Please think back to the last conversation you had with (1) about X.  
Please can you tell me what you told (1) about it

Code: did they say something/not say something

5.17.03 Did that affect how you thought about X?	0	1
--	---	---

5.17.04 If yes, how?

Derive a way of coding this

.....

.....

5.17.05 Did what they said affect how you felt?	0	1
5.17.06 If yes, how?		

Code: worse/better

.....

.....

5.17.07 Did what they said affect anything that you did?	0	1
5.17.08 If yes, how?		

Derive a coding system if possible, if not omit

5.17.15 Researcher's overall estimate of whether the conversation had any effect on the nature or quality of the belief

Ignores or rejects relevance	0
Decreases conviction/ dismisses belief	1
Accommodates into system/increases conviction	2

5.17.16 Researcher's overall estimate of whether the conversation had any effect on the affect of the patient

Rate each affect: made worse 2 made better 1, no effect 0, not applicable 8

- 5.17.12.1 Elated?
- 5.17.12.2 Unhappy / miserable / depressed?
- 5.17.12.3 Terrified / frightened?
- 5.17.12.8 Anxious / tense?
- 5.17.12.9 Angry?

---

## 6. PREOCCUPATION WITH CHOSEN BELIEFS

NB It may not be necessary to ask specific questions about this here, but the interviewer should rate preoccupation at the time of the interview, not attempt to estimate preoccupation retrospectively, e.g. at the time any act was committed.

None/thinks sometimes of past delusions only	0
Current delusion definitely present but can turn attention to other things	1
Current delusion takes up most of time. Preoccupied to the exclusion of many other matters/patient can hardly discuss anything but delusion	2

## 7. SYSTEMATISATION OF CHOSEN BELIEF

NB It may not be necessary to ask specific questions about this here, but the interviewer should rate systematisation at the time of the interview, not attempt to estimate preoccupation retrospectively, e.g. at the time any act was committed.

None	0
Delusions not elaborated into general system/ some systematic elaboration but substantial areas of experiences not affected	1
Interprets practically all experiences in delusion terms.	2

## 8. INSIGHT

***Do you think that seeing a psychiatrist might help you (has helped you) in any way?***

Accepts need to see a psychiatrist (regardless of reason)	= 0
No need to see a psychiatrist but will see one if asked	= 1
No need to see a psychiatrist and will only see one under duress	= 2

(To score '0' or '1' on this question or on item 8.04 the reasons given for wanting psychiatric help need not relate to the delusional belief)

### 8.04 Treatment (2)

***Do you think that medication might help you (has helped you) in any way? ... How?***

Accepts need for drug treatment (regardless of reason)	= 0
No need for drug treatment but has/will accept it when offered	= 1
Refusing to accept medication	= 2
No drug prescribed	= 9

#### 8.05 Self-protection

***How much have you discussed X with your doctor and the nurses on the ward?***

Refuses to discuss beliefs	= 0
Discusses beliefs only under direct questioning	= 1
Eager to discuss beliefs with all	= 2

#### 8.06 Illness

***Are you psychologically unwell in any way...is there anything wrong with your nerves?***

Accepts that has a mental illness or nervous problem which includes delusional belief	= 0
Accepts that has a mental illness or nervous problem but does not include delusional belief	= 1
Not ill; belief sound	= 2

**SECTIONS 8.07 – 8.10 ONLY TO BE RATED FOR THOSE SUBJECTS WHO HAVE ACTED VIOLENTLY OR DANGEROUSLY ON THEIR DELUSION**

Specify the action under consideration

.....

#### 8.07 Moral

***Looking back on (the behaviour X), do you now feel that you were justified, or were you wrong to do what you did?***

Accepts that behaviour or act was wrong, and feels remorse	= 0
Accepts that behaviour or act was wrong, but feels justified	= 1
Denies behaviour or act was wrong	= 2
Not applicable	= 9

#### 8.08 Legal

***Was (the behaviour X) against the law?***

Accepts illegality and now believes that should not have broken the law	= 0
Accepts illegality but feels justified in breaking the law	= 1
Does not consider the law to be relevant / denies illegality	= 2
Not applicable	= 9

#### 8.09 Risk

***How dangerous was (the behaviour X) ... would you take the same risk again?***

Recognises risk, and now feels the risk was not worth it	= 0
Recognises risk, but feels risk was worth it	= 1
Risk irrelevant, or does recognise any risk	= 2
Not applicable	= 9

#### 8.10 Reaction of others



***Why do you feel that (the people involved) responded to you in the way they did – were they right?***

Understands the reactions of others and accepts these are reasonable	= 0
Accepts the reactions of others but cannot agree with them	= 1
Cannot understand why others reacted to behaviour as they did	= 2
Not applicable	= 9

**Appendix 27: The MADS – Informants’ comparison table**

Variable	Patient	Relatives	Staff
<b>Delusion content</b> Code yes/no	01:Y, 02:Y, 03:Y, 04:Y, 05:Y, 06:Y, 07:Y, 08:Y, 09: Y, 10:Y, 11:Y, 12:Y, 13:Y, 14:Y, 15:Y, 16:Y, 17:Y, 18:Y, 19:Y, 20:Y, 21:Y, 22:Y, 23:Y, 24:Y, 25:Y, 26:Y, 27:Y, 28:Y, 29:Y, 30:Y, 31:Y, 32:Y, 33:Y, 34:Y, 35:Y, 36:Y	01:Y, 05:Y, 10:Y, 12:Y, 16:Y, 17:Y, 26:Y, 28:Y, 31:N*  *Relatives haven’t given a proper description – hence why rated as N.	01:Y, 02:Y, 04:Y, 05:Y, 06:Y, 07:Y, 08:Y, 09:Y, 10:Y, 12:Y, 13:Y, 14:Y, 15:Y, 17:Y, 20:Y, 26:Y, 27:Y, 30:Y, 31:Y, 32:Y, 33:Y, 36:Y
persecutory	03:Y, 04:Y, 05:Y, 06:Y, 07:Y, 10:Y, 11:Y, 15:Y, 16:Y, 21:Y, 28:Y, 30:Y, 31:Y, 32:Y, 33:Y, 34:Y, 36:Y	16:Y, 28:Y, 31:Y	04:Y, 05:Y, 06:Y, 07:Y, 08:Y, 15:Y, 20:Y, 30:Y, 31:Y, 32:Y, 33:Y, 36:Y
religious	02:Y, 08:Y, 09:Y, 13:Y, 14:Y, 26:Y, 27:Y, 35:Y	05:Y, 10:Y, 26:Y	02:Y, 13:Y, 14:Y, 26:Y, 27:Y
ecstatic			
other paranormal			
grandiose	12:Y, 17:Y, 18:Y, 19:Y, 23:Y, 29:Y	12:Y, 17:Y	12:Y, 17:Y
morbid jealousy	24:Y		
Hypochondriacal	25:Y		
catastrophic			
erotomania	01:Y, 20:Y	01:Y	01:Y, 09:Y, 10:Y
Conviction 1=absolutely/almost certain 0=quite certain/have some doubts/definitely doubt it 9=unknown	01:1, 02:1, 03:1, 04:0, 05:1, 06:1, 07:1, 08:1, 09:1, 10:1, 11:1, 12:1, 13:0, 14:1, 16:1, 17:1, 18:1, 19:1, 20:1, 21:1, 22:1, 23:1, 24:1, 25:0, 26:1, 27:1, 28:1, 29:1, 30:1, 31:1, 32:1, 33:1, 34:1, 35:1, 36:1	01:1, 05:1, 10:1, 12:1, 16:1, 17:1, 26:0, 28:1, 31:9	01:1, 02:1, 04:0, 05:1, 06:1, 07:1, 08:1, 09:1, 10:1, 12:1, 13:0, 14:1, 17:0, 20:1, 26:0, 27:1, 30:1, 31:1, 32:0, 33:0, 36:1

External event? 0=No, 1=Yes, Don't know = 9	01:0, 02:9, 03:1, 04:1, 05:1, 06:1, 07:1, 08:1, 09:9, 10:1, 11:9, 12:1, 13:1, 14:1, 16:0, 17:1, 18:1, 19:1, 20:1, 21:1, 22:1, 23:0, 24:1, 25:1, 26:1, 27:1, 28:1, 29:1, 30:0, 31:0, 32:0, 33:0, 34:1, 35:1, 36:0	01:1, 05:1, 10:1, 12:0, 16:9, 17:9, 26:0, 28:1, 31:1	01:1, 02:0, 04:0, 05:0, 06:0, 07:0, 08:1, 09:0, 10:0, 12:0, 13:0, 14:0, 17:0, 20:0, 26:0, 27:1, 30:1, 31:1, 32:0, 33:0, 36:0
Internal State? 0=No, 1=Yes, Don't know = 9	01:1, 02: , 03:1, 04:1, 05:1, 06:1, 07:1, 08:1, 09:1, 10:1, 11:1, 12:0, 13:1, 14:0, 16:1, 17:9, 18:1, 19:9, 20:1, 21:1, 22:1, 23:1, 24:0, 25:0, 26:0, 27:1, 28:1, 29:0, 30:9, 31:0, 32:1, 33:1, 34:9, 35:1, 36:0	01:1, 05:1, 10:1, 12:0, 16:1, 17:0, 26:1, 28:0, 31:9	01:1, 02:1, 04:0, 05:0, 06:1, 07:0, 08:0, 09:1, 10:0, 12:0, 13:0, 14:0, 17:0, 20:0, 26:1, 27:1, 30:1, 31:1, 32:0, 33:0, 36:1
Looked for evidence? 0=No, 1=Yes, Don't know = 9	01:1, 02:1, 03:0, 04:1, 05:1, 06:9, 07:1, 08:1, 09:0, 10:1, 11:1, 12:0, 13:1, 14:0, 16:0, 17:1, 18:1, 19:0, 20:9, 21:0, 22:0, 23:1, 24:1, 25:1, 26:1, 27:0, 28:0, 29:0, 30:1, 31:0, 32:0, 33:0, 34:1, 35:0, 36:0	01:1, 05:0, 10:1, 12:1, 16:0, 17:0, 26:1, 28:9, 31:9	01:1, 02:0, 04:0, 05:0, 06:0, 07:0, 08:0, 09:0, 10:0, 12:1, 13:0, 14:1, 17:0, 20:0, 26:1, 27:0, 30:0, 31:0, 32:0, 33:0, 36:1
Elated? 0=No, 1=Yes, 9=unknown	01:1, 02:0, 03:0, 04:0, 05:0, 06:0, 07:0, 08:1, 09:0, 10:0, 11:0, 12:1, 13:0, 14:1, 16:0, 17:1, 18:1, 19:1, 20:1, 21:0, 22:0, 23:1, 24:0, 25:9, 26:0, 27:0, 28:0, 29:1, 30:0, 31:0, 32:9, 33:0, 34:0, 35:0, 36:0	01:0, 05:0, 10:1, 12:1, 16:0, 17:1, 26:0, 28:0, 31:9	01:0, 02:0, 04:0, 05:0, 06:1, 07:0, 08:0, 09:1, 10:1, 12:1, 13:1, 14:0, 17:1, 20:0, 26:0, 27:0, 30:0, 31:0, 32:0, 33:0, 36:0
Unhappy? 0=No, 1=Yes, 9=unknown	01:0, 02:0, 03:1,	01:1, 05:1,	01:1, 02:1,

	04:1, 05:1, 06:1, 07:1, 08:0, 09:0, 10:1, 11:0, 12:0, 13:1, 14:1, 16:1, 17:0, 18:1, 19:0, 20:0, 21:1, 22:1, :0, 24:1, 25:0, 26:1, 27:1, 28:1, 29:0, 30:0, 31:1, 32:1, 33:1, 34:0, 35:1, 36:0	10:1, 12:0, 16:1, 17:0, 26:1, 28:1, 31:9	04:1, 05:0, 06:0, 07:1, 08:1, 09:1, 10:1, 12:9, 13:1, 14:1, 17:0, 20:1, 26:1, 27:1, 30:1, 31:1, 32:1, 33:1, 36:1
Terrified? 0=No, 1=Yes, 9=unknown	01:0, 02:1, 03:0, 04:1, 05:1, 06:1, 07:0, 08:0, 09:0, 10:1, 11:1, 12:0, 13:1, 14:1, 16:1, 17:0, 18:0, 19:0, 20:0, 21:1, 22:1, 23:0, 24:1, 25:0, 26:1, 27:1, 28:1, 29:0, 30:1, 31:0, 32:1, 33:1, 34:0, 35:1, 36:0	01:1, 05:1, 10:1, 12:0, 16:1, 17:0, 26:1, 28:1, 31:9	01:1, 02:1, 04:1, 05:0, 06:1, 07:1, 08:0, 09:0, 10:0, 12:9, 13:1, 14:0, 17:0, 20:1, 26:1, 27:1, 30:1, 31:1, 32:1, 33:0, 36:1
Anxious 0=No, 1=Yes, 9=unknown	01:1, 02:1, 03:1, 04:1, 05:1, 06:1, 07:1, 08:1, 09:0, 10:1, 11:1, 12:0, 13:1, 14:0, 16:1, 17:0, 18:0, 19:0, 20:0, 21:1, 22:1, 23:1, 24:1, 25:1, 26:1, 27:1, 28:1, 29:0, 30:1, 31:1, 32:1, 33:1, 34:1, 35:1, 36:1	01:1, 05:1, 10:1, 12:0, 16:1, 17:0, 26:1, 28:1, 31:9	01:1, 02:1, 04:1, 05:0, 06:1, 07:1, 08:0, 09:1, 10:1, 12:9, 13:1, 14:0, 17:0, 20:1, 26:1, 27:1, 30:1, 31:1, 32:1, 33:1, 36:1
Angry 0=No, 1=Yes, 9=unknown	01:0, 02:1, 03:1, 04:1, 05:1, 06:1, 07:0, 08:0, 09:1, 10:9, 11:0, 12:0, 13:1, 14:1, 16:1, 17:0, 18:0, 19:0, 20:0, 21:1, 22:1, 23:0, 24:1, 25:0, 26:1, 27:1, 28:1, 29:0, 30:0, 31:1, 32:1, 33:1, 34:1, 35:1, 36:1	01:1, 05:1, 10:1, 12:0, 16:1, 17:0, 26:1, 28:1, 31:9	01:0, 02:0, 04:0, 05:1, 06:1, 07:0, 08:0, 09:1, 10:1, 12:9, 13:0, 14:0, 17:0, 20:0, 26:1, 27:1, 30:1, 31:1, 32:1, 33:1, 36:1
Does X make you do anything in particular? 0=No, 1=Yes, 9=unknown	01:1, 02:1, 03:1, 04:0, 05:1, 06:1,	No relatives or staff gave answers for these questions	

	07:1, 08:1, 09:1, 10:1, 11:1, 12:1, 13:1, 14:0, 15:0, 16:0, 17:1, 18:1, 19:1, 20:1, 21:1, 22:9, 23:1, 24:1, 25:1, 26:1, 27:1, 28:1, 29:1, 30:1, 31:0, 32:1, 33:1, 34:1, 35:1, 36:1	– perhaps not asked by the researcher as deemed too general.  Detailed qualitative answers given by patients.	
Have you told anyone about X? 0=Did not occur 1=Sometimes/often/occasionally 9=N/A	01:1, 02:1, 03:1, 04:1, 05:1, 06:1, 07:1, 08:1, 09:1, 10:1, 11:0, 12:1, 13:1, 14:1, 15:1, 16:0, 17:1, 18:1, 19:1, 20:1, 21:1, 22:9, 23:1, 24:1, 25:1, 26:1, 27:1, 28:1, 29:0, 30:0, 31:1, 32:1, 33:1, 34:1, 35:1, 36:1	01:1, 05:1, 10:1, 12:1, 16:1, 17:1, 26:1, 28:0, 31:0	01:1, 02:1, 04:1, 05:1, 06:1, 07:1, 08:1, 09:1, 10:9, 12:1, 13:1, 14:1, 17:1, 20:1, 26:1, 27:1, 30:0, 31:1, 32:1, 33:1, 36:1
Have you written to anyone? 0=Did not occur 1=Sometimes/often/occasionally 9=N/A	01:0, 02:0, 03:0, 04:1, 05:0, 06:0, 07:0, 08:0, 09:1, 10:0, 11:0, 12:0, 13:0, 14:0, 15:0, 16:0, 17:0, 18:0, 19:0, 20:0, 21:0, 22:9, 23:0, 24:0, 25:0, 26:0, 27:0, 28:0, 29:1, 30:0, 31:0, 32:0, 33:0, 34:1, 35:0, 36:0	01:0, 05:0, 10:1, 12:0, 16:0, 17:0, 26:0, 28:0, 31:9	01:0, 02:0, 04:0, 05:0, 06:0, 07:0, 08:0, 09:1, 10:0, 12:0, 13:0, 14:0, 17:0, 20:1, 26:1, 27:0, 30:0, 31:1, 32:1, 33:0, 36:1
Have you tried to stop X from happening? 0=Did not occur 1=Sometimes/often/occasionally 9=N/A, DK	01:0, 02:9, 03:1, 04:1, 05:1, 06:0, 07:1, 08:1, 09:0, 10:1, 11:0, 12:0, 13:1, 14:0, 15:0, 16:0, 17:0, 18:0, 19:0, 20:0, 21:1, 22:9, 23:1, 24:1, 25:1, 26:0, 27:1, 28:1, 29:9, 30:0, 31:1, 32:0, 33:1, 34:9, 35:1, 36:0	01:1, 05:0, 10:1, 12:0, 16:1, 17:0, 26:1, 28:0, 31:9	01:1, 02:1, 04:0, 05:0, 06:0, 07:0, 08:0, 09:0, 10:0, 12:0, 13:0, 14:0, 17:0, 20:0, 26:0, 27:1, 30:1, 31:0, 32:1, 33:1, 36:0
Have you tried to protect yourself in any way? 0=Did not occur 1=Sometimes/often/occasionally	01:1, 02:0, 03:0, 04:0, 05:1, 06:1, 07:1, 08:0, 09:0,	01:0, 05:0, 10:1, 12:0, 16:1, 17:0,	01:0, 02:0, 04:0, 05:0, 06:0, 07:0,

9=N/A	10:1, 11:1, 12:0, 13:1, 14:0, 15:1, 16:1, 17:0, 18:1, 19:0, 20:0, 21:1, 22:9, 23:9, 24:0, 25:9, 26:1, 27:1, 28:1, 29:9, 30:1, 31:1, 32:0, 33:9, 34:1, 35:1, 36:0	26:1, 28:0, 31:9	08:0, 09:0, 10:0, 12:0, 13:0, 14:0, 17:0, 20:0, 26:1, 27:1, 30:1, 31:0, 32:0, 33:1, 36:1
Specify			
Does X make you lose your temper? 0=Did not occur 1=Sometimes/often/occasionally 9=N/A	01:0, 02:1, 03:1, 04:1, 05:1, 06:1, 07:0, 08:1, 09:0, 10:1, 11:0, 12:0, 13:1, 14:1, 15:0, 16:0, 17:0, 18:0, 19:0, 20:0, 21:1, 22:9, 23:0, 24:1, 25:0, 26:1, 27:1, 28:1, 29:0, 30:0, 31:1, 32:1, 33:1, 34:1, 35:1, 36:0	01:1, 05:1, 10:1, 12:1, 16:1, 17:0, 26:0, 28:0, 31:9	01:0, 02:1, 04:0, 05:1, 06:0, 07:0, 08:0, 09:1, 10:0, 12:0, 13:0, 14:0, 17:0, 20:1, 26:1, 27:1, 30:1, 31:0, 32:0, 33:1, 36:1
Have you broken anything because of this? 0=Did not occur 1=Sometimes/often/occasionally 9=N/A	01:1, 02:1, 03:1, 04:1, 05:0, 06:0, 07:0, 08:0, 09:0, 10:0, 11:0, 12:0, 13:0, 14:0, 15:0, 16:1, 17:0, 18:0, 19:0, 20:0, 21:1, 22:9, 23:0, 24:1, 25:0, 26:0, 27:1, 28:1, 29:0, 30:0, 31:1, 32:0, 33:1, 34:0, 35:0, 36:0	001:1, 05:1, 10:1, 12:0, 16:1, 17:0, 26:0, 28:0, 31:9	01:0, 02:0, 04:0, 05:0, 06:0, 07:0, 08:0, 09:1, 10:0, 12:0, 13:0, 14:0, 17:0, 20:0, 26:0, 27:1, 30:0, 31:0, 32:0, 33:1, 36:1
Have you felt like hitting anyone because of it? 0=Did not occur 1=Sometimes/often/occasionally 9=N/A	01:0, 02:0, 03:1, 04:1, 05:1, 06:1, 07:0, 08:0, 09:1, 10:0, 11:0, 12:0, 13:1, 14:1, 15:1, 16:9, 17:0, 18:0, 19:0, 20:0, 21:1, 22:9, 23:0, 24:1, 25:0, 26:0, 27:1, 28:1, 29:0, 30:1, 31:1, 32:1, 33:1, 34:1, 35:1, 36:0	01:9, 05:1, 10:1, 12:0, 16:1, 17:0, 26:0, 28:0, 31:9	01:0, 02:1, 04:0, 05:0, 06:0, 07:0, 08:0, 09:1, 10:0, 12:0, 13:0, 14:0, 17:0, 20:0, 26:0, 27:1, 30:0, 31:0, 32:0, 33:1, 36:9
Have you hit anyone because of it? 0=Did not occur 1=Sometimes/often/occasionally	01:0, 02:0, 03:0, 04:0, 05:0, 06:0, 07:0, 08:0, 09:1,	01:0, 05:0, 10:1, 12:0, 16:0, 17:0,	01:0, 02:0, 04:0, 05:0, 06:0, 07:0,

9=N/A	10:0, 11:0, 12:0, 13:0, 14:0, 15:0, 16:0, 17:1, 18:0, 19:0, 20:0, 21:0, 22:9, 23:0, 24:0, 25:0, 26:0, 27:1, 28:1, 29:0, 30:0, 31:0, 32:1, 33:1, 34:1, 35:1, 36:0	26:0, 28:0, 31:9	08:0, 09:0, 10:0, 12:0, 13:0, 14:0, 17:0, 20:0, 26:0, 27:0, 30:0, 31:0, 32:0, 33:0, 36:0
Specify			
Have you tried to hurt yourself or harmed yourself accidentally because of X? 0=Did not occur 1=Sometimes/often/occasionally 9=NA/Missing	01:0, 02:1, 03:0, 04:0, 05:0, 06:0, 07:0, 08:1, 09:0, 10:9, 11:0, 12:0, 13:0, 14:0, 15:1, 16:1, 17:0, 18:0, 19:0, 20:0, 21:0, 22:9, 23:0, 24:1, 25:0, 26:0, 27:1, 28:0, 29:0, 30:0, 31:1, 32:1, 33:1, 34:0, 35:1, 36:0	01:1, 05:1, 10:1, 12:0, 16:0, 17:0, 26:0, 28:0, 31:0	01:0, 02:1, 04:0, 05:0, 06:0, 07:0, 08:0, 09:0, 10:0, 12:0, 13:0, 14:1, 17:0, 20:1, 26:0, 27:1, 30:0, 31:0, 32:0, 33:0, 36:0
Specify			
Have you tried to move or leave your house (area) because of X? 0=Did not occur 1=Sometimes/often/occasionally 9=NA/Missing	01:0, 02:0, 03:1, 04:0, 05:1, 06:1, 07:1, 08:1, 09:0, 10:1, 11:0, 12:0, 13:0, 14:1, 15:0, 16:1, 17:0, 18:0, 19:1, 20:0, 21:0, 22:9, 23:0, 24:0, 25:1, 26:1, 27:0, 28:1, 29:9, 30:0, 31:1, 32:0, 33:1, 34:0, 35:1, 36:0	01:1, 05:1, 10:1, 12:1, 16:0, 17:0, 26:0, 28:0, 31:0	01:0, 02:1, 04:0, 05:0, 06:0, 07:0, 08:0, 09:0, 10:0, 12:0, 13:0, 14:9, 17:0, 20:1, 26:0, 27:0, 30:0, 31:0, 32:0, 33:0, 36:0
Have any other changes resulted? 0=Did not occur 1=Sometimes/often/occasionally 9=NA/Missing	01:1, 02:0, 03:0, 04:0, 05:1, 07:1, 06:9, 08:1, 09:1, 10:0, 11:0, 12:0, 13:0, 14:1, 15:0, 16:1, 17:0, 18:0, 19:1, 20:0, 21:9, 22:9, 23:0, 24:1, 25:0, 26:1, 27:1, 28:1, 29:1, 30:1, 31:0, 32:0, 33:1, 34:0, 35:1, 36:0	01:1, 05:0, 10:9, 12:1, 16:9, 17:0, 26:1, 28:0, 31:0	01:0, 02:1, 04:0, 05:0, 06:0, 07:0, 08:9, 09:0, 10:0, 12:0, 13:0, 14:0, 17:0, 20:9, 26:0, 27:0, 30:0, 31:0, 32:0, 33:1, 36:0
Specify			
Do the voices tell you to do	01:9, 02:9, 03:1,	01:9, 05:1,	01:0, 06:1,

anything? 0=Did not occur 1=Sometimes/often/occasionally 9=N/A	04:0, 05:1, 06:1, 07:0, 08:9, 09:9, 10:1, 11:9, 12:9, 13:9, 14:9, 16:1, 17:9, 18:0, 19:9, 20:0, 21:0, 22:9, 23:0, 24:9, 25:9, 26:9, 27:1, 28:9, 29:9, 30:1, 31:9, 32:1, 33:1, 34:9, 35:1, 36:9	10:1, 12:9, 16:1, 17:0, 26:9, 28:9, 31:0	09:0, 10:9, 12:9, 13:0, 14:1, 20:1, 26:0, 27:1, 30:1, 31:0, 32:0, 33:1, 36:0
Do you have to obey? 0=Did not occur 1=Sometimes/often/occasionally 9=N/A	01:9, 02:9, 03:1, 04:0, 05:1, 06:0, 07:0, 08:9, 09:9, 10:0, 11:9, 12:9, 13:9, 14:9, 16:1, 17:9, 18:0, 19:9, 20:0, 21:9, 22:9, 23:0, 24:9, 25:9, 26:9, 27:1, 28:9, 29:9, 30:1, 31:9, 32:1, 33:1, 34:9, 35:1, 36:9	01:9, 05:1, 10:1, 12:9, 16:1, 17:0, 26:9, 28:9, 31:0	01:1, 06:1, 09:1, 10:9, 12:9, 13:1, 14:1, 20:0, 26:0, 27:0, 30:0, 31:0, 32:0, 33:1, 36:0
Do you do anything to escape them? 0=Did not occur 1=Sometimes/often/occasionally 9=N/A	01:9, 02:9, 03:1, 04:1, 05:1, 06:0, 07:1, 08:9, 09:9, 10:1, 11:9, 12:9, 13:9, 14:9, 16:DK, 17:9, 18:1, 19:9, 20:0, 21:1, 22:9, 23:0, 24:9, 25:9, 26:9, 27:1, 28:9, 29:9, 30:1, 31:9, 32:0, 33:1, 34:9, 35:1, 36:9	01:9, 10:9, 12:9, 16:DK, 17:0, 26:9, 28:9, 31:0	06:0, 09:9, 10:9, 12:9, 13:DK, 14:1, 20:9, 26:0, 27:1, 30:0, 31:0, 32:1, 33:1, 36:0
Do the voices have any relation to X? 0=Did not occur 1=Sometimes/often/occasionally 9=N/A	01:9, 02:9, 03:1, 04:1, 05:1, 06:1, 07:1, 08:9, 09:9, 10:1, 11:9, 12:9, 13:9, 14:9, 16:1, 17:9, 18:0, 19:9, 20:0, 21:1, 22:9, 23:0, 24:9, 25:9, 26:9, 27:1, 28:9, 29:9, 30:1, 31:9, 32:1, 33:1, 34:9, 35:1, 36:9	01:9, 10:9, 12:9, 16:DK, 17:0, 26:9, 28:9, 31:0	06:9, 09:9, 10:9, 12:9, 13:DK, 14:0, 20:9, 26:0, 27:1, 30:1, 31:1, 32:0, 33:0, 36:0
Tell me how they relate			
Can you remember if the voices	01:9, 02:9, 03:1,	01:9, 10:9,	06:9, 09:9,



were there before? 1=yes, 0=no, 9=don't know	04:1, 05:0, 06:9, 07:9, 08:9, 09:9, 10:1, 11:9, 12:9, 13:9, 14:9, 16:9, 17:9, 18:9, 19:9, 20:9, 21:9, 22:9, 23:0, 24:9, 25:9, 26:9, 27:9, 28:9, 29:9, 30:0, 31:9, 32:9, 33:9, 34:9, 35:9, 36:9	12:9, 16:9, 17:0, 26:9, 28:9, 31:9	10:9, 12:9, 13:DK, 14:1, 20:9, 26:0, 27:9, 30:1, 31:9, 32:0, 33:1, 36:0
Has X stopped you from meeting friends 0=Did not occur 1=Sometimes/often/occasionally 9=NA/missing	01:1, 02:1, 03:1, 04:1, 05:0, 06:1, 07:1, 08:1, 09:0, 10:1, 11:0, 12:0, 13:0, 14:0, 15:1, 16:1, 17:0, 18:9, 19:0, 20:1, 21:1, 22:9, 23:0, 24:1, 25:1, 26:0, 27:1, 28:1, 29:0, 30:1, 31:1, 32:0, 33:1, 34:1, 35:1, 36:0	01:1, 05:1, 10:1, 12:0, 16:9, 17:0, 26:1, 28:0, 31:0	01:1, 02:1, 04:0, 05:0, 06:1, 07:0, 08:1, 09:0, 10:0, 12:0, 13:0, 14:1, 17:0, 20:1, 26:0, 27:1, 30:1, 31:1, 32:0, 33:1, 36:0
Has X stopped you watching TV or listening to radio? 0=Did not occur 1=Sometimes/often/occasionally 9=NA/missing	01:1, 02:1, 03:0, 04:1, 05:1, 06:1, 07:0, 08:1, 09:0, 10:1, 11:9, 12:9, 13:0, 14:0, 15:1, 16:1, 17:0, 18:0, 19:0, 20:1, 21:1, 22:9, 23:0, 24:1, 25:0, 26:0, 27:1, 28:1, 29:0, 30:1, 31:0, 32:1, 33:1, 34:0, 35:1, 36:0	01:1, 05:1, 10:1, 12:0, 16:1, 17:0, 26:1, 28:0, 31:0	01:1, 02:1, 04:0, 05:0, 06:1, 07:0, 08:1, 09:0, 10:0, 12:0, 13:0, 14:1, 17:0, 20:0, 26:0, 27:1, 30:0, 31:1, 32:1, 33:1, 36:0
Has X stopped you from eating/drinking anything 0=Did not occur 1=Sometimes/often/occasionally 9=NA/missing	01:0, 02:0, 03:0, 04:0, 05:0, 06:0, 07:0, 08:1, 09:0, 10:0, 11:0, 12:0, 13:0, 14:0, 15:1, 16:1, 17:0, 18:1, 19:0, 20:1, 21:1, 22:9, 23:0, 24:1, 25:1, 26:0, 27:0, 28:1, 29:0, 30:0, 31:0, 32:0, 33:0, 34:0, 35:0, 36:0	01:1, 05:0, 10:1, 12:1, 16:1, 17:0, 26:0, 28:0, 31:0	01:0, 02:0, 04:0, 05:0, 06:0, 07:0, 08:1, 09:0, 10:0, 12:0, 13:0, 14:1, 17:0, 20:1, 26:0, 27:0, 30:1, 31:0, 32:0, 33:1, 36:0
Has X stopped you from using public transport 0=Did not occur	01:1, 02:0, 03:0, 04:1, 05:1, 06:0,	01:1, 05:1, 10:1, 12:0,	01:0, 02:9, 04:0, 05:0,

1=Sometimes/often/occasionally 9=NA/missing	07:0, 08:0, 09:9, 10:1, 11:0, 12:1, 13:1, 14:0, 15:0, 16:1, 17:0, 18:1, 19:0, 20:1, 21:0, 22:9, 23:1, 24:1, 25:1, 26:0, 27:0, 28:1, 29:0, 30:1, 31:1, 32:1, 33:1, 34:1, 35:1, 36:0	16:1, 17:0, 26:1, 28:0, 31:0	06:9, 07:0, 08:0, 09:9, 10:0, 12:9, 13:9, 14:0, 17:0, 20:0, 26:0, 27:9, 30:0, 31:0, 32:9, 33:9, 36:0
Stopped you from taking medication 0=Did not occur 1=Sometimes/often/occasionally 9=NA/missing	01:0, 02:0, 03:0, 04:0, 05:0, 06:0, 07:1, 08:0, 09:0, 10:1, 11:1, 12:0, 13:0, 14:0, 15:1, 16:1, 17:1, 18:0, 19:1, 20:0, 21:0, 22:9, 23:0, 24:1, 25:0, 26:1, 27:0, 28:0, 29:1, 30:0, 31:9, 32:1, 33:0, 34:0, 35:1, 36:9	01:0, 05:0, 10:1, 12:1, 16:0, 17:0, 26:9, 28:0, 31:0	01:0, 02:0, 04:0, 05:0, 06:0, 07:0, 08:0, 09:9, 10:0, 12:0, 13:0, 14:1, 17:1, 20:0, 26:0, 27:0, 30:0, 31:0, 32:0, 33:0, 36:0
Stopped you from going to hospital/doctor on an outpatient basis 0=Did not occur 1=Sometimes/often/occasionally 9=NA/missing	01:0, 02:0, 03:0, 04:0, 05:0, 06:1, 07:1, 08:0, 09:1, 10:9, 11:1, 12:0, 13:0, 14:1, 15:0, 16:1, 17:1, 18:1, 19:1, 20:0, 21:0, 22:9, 23:1, 24:1, 25:9, 26:1, 27:0, 28:1, 29:9, 30:9, 31:9, 32:1, 33:0, 34:0, 35:1, 36:0	01:0, 05:1, 10:1, 12:1, 16:0, 17:0, 26:1, 28:9, 31:9	01:0, 02:0, 04:0, 05:0, 06:0, 07:0, 08:0, 09:1, 10:0, 12:0, 13:0, 14:0, 17:0, 20:0, 26:0, 27:9, 30:9, 31:9, 32:9, 33:9, 36:0
Is there any thing else that X has stopped you from doing 0=Did not occur 1=Sometimes/often/occasionally 9=NA/missing	01:1, 02:1, 03:1, 04:0, 05:0, 06:9, 07:0, 08:1, 09:1, 10:0, 11:9, 12:0, 13:0, 14:0, 15:0, 16:1, 17:0, 18:1, 19:0, 20:0, 21:9, 22:9, 23:0, 24:0, 25:0, 26:1, 27:0, 28:1, 29:0, 30:0, 31:0, 32:0, 33:0, 34:9, 35:0, 36:0	01:0, 05:9, 10:9, 12:9, 16:9, 17:0, 26:1, 28:1, 31:9	01:0, 02:0, 04:0, 05:0, 06:0, 07:0, 08:0, 09:0, 10:0, 12:0, 13:0, 14:0, 17:0, 20:0, 26:9, 27:0, 30:0, 31:9, 32:9, 33:0, 36:0
How far do you think that others share your beliefs? 1=Completely/to a considerable extent/to some extent	01:1, 02:1, 03:1, 04:0, 05:0, 06:0, 07:0, 08:1, 09:0,	01:1, 05:1, 10:1, 12:0, 16:1, 17:1,	01:0, 02:1, 04:0, 05:0, 06:1, 07:0,

0=Hardly at all/not at all	10:0, 11:0, 12:1, 13:0, 14:0, 16:0, 17:0, 18:1, 19:0, 20:1, 21:0, 22:9, 23:0, 24:0, 25:0, 26:1, 27:1, 28:0, 29:0, 30:0, 31:0, 32:0, 33:0, 34:1, 35:0, 36:1	26:0, 28:0, 31:9	08:1, 09:0, 12:0, 13:0, 14:0, 17:1, 20:0, 26:1, 27:0, 30:0, 31:1, 32:0, 33:1, 36:1
Do you ever have arguments about your beliefs? 1=Frequently/often/sometimes 0=Hardly/never	01:1, 02:0, 03:0, 04:1, 05:1, 06:0, 07:1, 08:1, 09:0, 10:0, 11:0, 12:0, 13:0, 14:0, 16:0, 17:0, 18:1, 19:0, 20:0, 21:1, 22:9, 23:0, 24:1, 25:0, 26:1, 27:0, 28:1, 29:1, 30:1, 31:0, 32:0, 33:1, 34:0, 35:1, 36:0	01:1, 05:1, 10:1, 12:0, 16:0, 17:1, 26:1, 28:1, 31:0	01:1, 02:1, 04:0, 05:1, 06:1, 07:0, 08:0, 09:1, 12:0, 13:0, 14:1, 17:1, 20:0, 26:1, 27:0, 30:0, 31:1, 32:0, 33:1, 36:0
Do you speak about X with other people 1=Yes 0=No	01:1, 02:1, 03:0, 04:1, 05:1, 06:1, 07:1, 08:1, 09:0, 10:1, 11:0, 12:1, 13:1, 14:1, 16:1, 17:1, 18:1, 19:1, 20:1, 21:0, 22:9, 23:1, 24:1, 25:1, 26:1, 27:1, 28:1, 29:1, 30:1, 31:1, 32:1, 33:1, 34:1, 35:1, 36:1	01:1, 05:1, 10:1, 12:1, 16:1, 17:1, 26:0, 28:1, 31:0	01:1, 02:1, 04:1, 05:1, 06:1, 07:1, 08:1, 09:1, 12:1, 13:1, 14:1, 17:1, 20:1, 26:1, 27:1, 30:1, 31:1, 32:1, 33:1, 36:1
Can you give me an estimate of how often that happens? 2=Frequently/quite often 1=Sometimes/once or twice ever 0=Never	01:2, 02:1, 03:0, 04:1, 05:2, 06:2, 07:1, 08:1, 09:0, 10:DK, 11:0, 12:DK, 13:2, 14:1, 16:1, 17:2, 18:2, 19:2, 20:2, 21:9, 22:9, 23:2, 24:1, 25:1, 26:2, 27:1, 28:2, 29:1, 30:1, 31:1, 32:1, 33:1, 34:1, 35:1, 36:1	01:2, 05:1, 10:2, 12:2, 16:1, 17:2, 26:0, 28:2, 31:9	01:2, 02:2, 04:1, 05:1, 06:1, 07:2, 08:2, 09:2, 12:2, 13:2, 14:2, 17:2, 20:2, 26:2, 27:1, 30:1, 31:2, 32:1, 33:2, 36:2
List all people who you would talk with about X 3=professional person 2=person from social circle 1=both	01:1, 02:1, 04:1, 05:1, 06:3, 07:2, 08:1, 09:0, 10:2, 11:0, 12:1, 13:1,	01:1, 05:1, 12:9, 16:1, 17:1, 26:0, 28:9, 31:9	01:1, 02:1, 04:3, 05:1, 06:3, 08:3, 09:1, 12:3,

0=none 9=DK/NA	14:3, 16:2, 17:2, 18:1, 19:1, 20:1, 21:9, 22:9, 23:3, 24:1, 25:3, 26:1, 27:3, 28:1, 29:1, 30:1, 31:3, 32:1, 33:3, 34:1, 35:1, 36:1		13:1, 14:3, 17:3, 20:3, 26:1, 27:3, 30:3, 31:1, 32:1, 33:1, 36:3
Relationship			
How often in last month have you spoke to person from social circle (1) 2=Frequently/quite often 1=Sometimes/once or twice ever 0=Never	01:2, 02:0, 03:0, 04:1, 05:1, 06:0, 07:1, 08:2, 09:0, 10:1, 11:0, 12:2, 13:2, 14:0, 16:2, 17:2, 18:1, 19:2, 20:2, 21:0, 22:9, 23:0, 24:1, 25:0, 26:2, 27:0, 28:1, 29:1, 30:0, 31:9, 32:1, 33:0, 34:1, 35:0, 36:1	01:2, 05:2, 10:2, 12:2, 16:2, 17:2, 26:0, 28:9, 31:0	01:2, 02:2, 04:0, 05:2, 06:1, 07:1, 08:2, 09:DK, 12:2, 13:2, 14:0, 17:0, 20:2, 26:DK, 27:0, 30:0, 31:2, 32:1, 33:2, 36:0
If never to above specify when			
How often in the last month have you spoke to professional person (2) 2=Frequently/quite often 1=Sometimes/once or twice ever 0=Never	01:2, 02:0, 03:0, 05:1, 06:2, 07:0, 08:1, 09:0, 10:0, 11:0, 12:1, 13:2, 14:1, 16:0, 17:0, 18:0, 19:2, 20:2, 21:0, 22:9, 23:1, 24:1, 25:1, 26:1, 27:1, 28:1, 29:1, 30:0, 31:9, 32:1, 33:1, 34:1, 35:2, 36:1	01:2, 10:2, 12:2, 16:2, 17:1, 26:0, 28:9, 31:9	01:2, 02:2, 04:2, 05:2, 06:9, 07:9, 09:2, 12:2, 13:2, 14:2, 17:2, 26:2, 27:1, 30:1, 31:2, 32:2, 33:2, 36:2
If never to above specify when			
What did (1) tell you about X in your last conversation 1=They said something 0=They said nothing 9=Don't know/NA	01:1, 02:9, 03:9, 04:1, 05:1, 09:9, 10:1, 11:9, 12:0, 13:1, 14:9, 16:1, 17:0, 18:1, 19:1, 20:1, 21:9, 22:9, 23:9, 24:1, 25:9, 26:1, 27:9, 28:1, 29:0, 30:9, 31:9, 32:1, 33:9, 34:0, 35:9, 36:9	28:1, 31:9	26:1, 27:1, 30:1, 31:1, 32:1, 33:1, 36:1
Did it affect how you thought about X? 1=Yes	01:1, 04:0, 05:1, 10:0, 11:9, 12:1, 13:1, 14:9, 16:1,	01:0, 05:1, 10:0, 12:0, 16:1, 17:0,	01:0, 02:1, 04:1, 05:0, 06:1, 07:0,

0=No 9=N/A	17:0, 18:1, 19:1, 20:1, 21:9, 22:9, 23:9, 24:0, 25:9, 26:1, 27:9, 28:1, 29:0, 30:9, 31:9, 32:0, 33:9, 34:0, 35:9, 36:9	28:0, 31:9	08:0, 09:0, 12:0, 13:1, 14:0, 17:0, 20:0, 26:0, 27:0, 30:1, 31:0, 32:1, 33:0, 36:0
How? 2=made belief stronger 1=made belief weaker 0=no effect 9=N/A	05:2, 11:9, 12:2, 14:9, 16:0, 18:2, 19:2, 20:2, 21:9, 22:9, 23:9, 24:9, 25:9, 26:9, 27:9, 28:1, 29:0, 30:9, 31:9, 32:0, 33:9, 34:0, 35:9, 36:9	01:0, 28:0, 31:9	01:0, 05:0, 27:0, 30:1, 31:0, 32:1, 33:0, 36:0
Did what they say affect how you felt? 1=yes 0=no 9=N/A	01:1, 04:0, 05:1, 10:1, 11:9, 12:1, 13:1, 14:9, 16:0, 17:1, 18:1, 19:1, 20:1, 21:9, 22:9, 23:9, 24:1, 25:9, 26:1, 27:9, 28:1, 29:1, 30:9, 31:9, 32:1, 33:9, 34:1, 35:9, 36:9	01:0, 05:0, 10:0, 12:1, 16:1, 17:1, 28:1, 31:9	01:0, 02:1, 04:1, 05:0, 06:1, 07:1, 08:0, 09:1, 12:0, 13:1, 14:0, 17:0, 20:0, 26:0, 27:1, 30:0, 31:0, 32:1, 33:1, 36:0
How? 2=felt better 1=felt worse 0=no effect 9=N/A	01:0, 04:0, 05:1, 10:1, 11:9, 12:2, 13:2, 14:9, 16:9, 17:2, 18:1, 19:2, 20:2, 21:9, 22:9, 23:9, 24:1, 25:9, 26:1, 27:9, 28:2, 29:1, 30:9, 31:9, 32:2, 33:9, 34:2, 35:9, 36:9	01:0, 28:1, 31:9	01:0, 27:1, 30:0, 31:0, 32:2, 33:1, 36:0
Did it affect anything else? 1=Yes 0=No 9=N/A	01:0, 04:0, 05:0, 10:0, 11:9, 12:0, 13:0, 14:9, 16:9, 17:0, 18:0, 19:0, 20:0, 21:9, 22:9, 23:9, 24:0, 25:9, 26:0, 27:9, 28:0, 29:0, 30:9, 31:9, 32:0, 33:9, 34:0, 35:9, 36:9	01:1, 05:1, 10:0, 12:0, 16:0, 17:0, 28:0, 31:9	01:0, 02:1, 04:0, 05:0, 06:0, 07:0, 08:1, 09:0, 12:0, 13:0, 14:1, 17:0, 20:0, 26:0, 27:0, 30:0, 31:0, 32:1, 33:0, 36:0
How?			
Researcher obs: Elated 2=made worse	01:0, 04:0, 05:0, 10:0, 11:9, 12:2,	01:9, 10:9, 12:9, 16:9,	01:0, 02:0, 05:0, 06:1,

1=made better 0=no effect 9=NA/unknown	13:0, 14:9, 16:0, 17:2, 18:0, 19:2, 20:9, 21:9, 22:9, 23:9, 24:0, 25:9, 26:0, 27:9, 28:0, 29:0, 30:9, 31:9, 32:0, 33:9, 34:0, 35:9, 36:9	17:0, 28:0, 31:9	07:0, 08:0, 09:0, 12:9, 13:0, 14:0, 17:0, 20:0, 26:0, 27:0, 30:0, 31:0, 32:0, 33:0, 36:9
Unhappy/Miserable/ Depressed 2=made worse 1=made better 0=no effect 9=N/A	01:0, 04:0, 05:2, 10:0, 11:9, 12:9, 13:0, 14:9, 16:2, 17:9, 18:2, 19:9, 20:0, 21:9, 22:9, 23:9, 24:1, 25:9, 26:0, 27:9, 28:0, 29:0, 30:9, 31:9, 32:0, 33:9, 34:0, 35:9, 36:9	01:9, 05:2, 10:2, 12:2, 16:9, 17:0, 28:2, 31:9	01:0, 02:1, 04:0, 05:0, 06:0, 07:0, 08:0, 09:0, 12:9, 13:1, 14:0, 17:0, 20:0, 26:0, 27:0, 30:0, 31:0, 32:1, 33:0, 36:9
Terrified/ frightened 2=made worse 1=made better 0=no effect 9=N/A	01:0, 04:0, 05:0, 10:2, 11:9, 12:0, 13:0, 14:9, 16:0, 17:0, 18:0, 19:9, 20:2, 21:9, 22:9, 23:9, 24:0, 25:9, 26:0, 27:9, 28:0, 29:0, 30:9, 31:9, 32:0, 33:9, 34:0, 35:9, 36:9	01:9, 05:2, 10:9, 12:9, 16:9, 17:0, 28:0, 31:9	01:0, 02:1, 04:1, 05:0, 06:0, 07:0, 08:0, 09:0, 12:9, 13:0, 14:0, 17:0, 20:0, 26:0, 27:0, 30:0, 31:0, 32:1, 33:0, 36:9
Anxious/tense 2=made worse 1=made better 0=no effect 9=N/A	01:2, 04:0, 05:2, 10:2, 11:9, 12:0, 13:0, 14:9, 16:0, 17:0, 18:2, 19:9, 20:9, 21:9, 22:9, 23:9, 24:1, 25:9, 26:2, 27:9, 28:0, 29:0, 30:9, 31:9, 32:0, 33:9, 34:0, 35:9, 36:9	01:9, 05:2, 10:2, 12:9, 16:2, 17:0, 28:0, 31:9	01:2, 02:1, 04:1, 05:0, 06:0, 07:1, 08:1, 09:1, 12:9, 13:1, 14:0, 17:0, 20:0, 26:0, 27:0, 30:0, 31:0, 32:1, 33:0, 36:9
Angry? 2=made worse 1=made better 0=no effect 9=N/A	01:0, 04:0, 05:0, 10:2, 11:9, 12:0, 13:0, 14:9, 16:0, 17:0, 18:2, 19:9, 20:9, 21:9, 22:9, 23:9, 24:1, 25:9, 26:2, 27:9, 28:0, 29:0, 30:9, 31:9, 32:0, 33:9, 34:0, 35:9, 36:9	01:9, 05:2, 10:2, 12:9, 16:9, 17:0, 28:2, 31:9	02:0, 05:0, 06:0, 07:0, 08:0, 12:9, 13:9, 14:0, 17:0, 20:0, 26:0, 27:0, 30:0, 31:0, 32:1, 33:0, 36:9
What did (2) tell you about X in	01:1, 05:1, 06:1,		

your last conversation 1=They said something 0=They said nothing 9=N/A	11:9, 12:1, 13:DK, 14:0, 19:1, 20:1, , 22:9, 23:0, 24:1, 25:9, 26:1, 27:1, 28:1, 29:1, 30:9, 31:1, 32:0, 33:1, 34:1, 35:1, 36:1		
Did it affect how you thought about X? 1=Yes 0=No 9=N/A	01:1, 05:1, 06:0, 11:9, 12:0, 13:9, 14:0, 19:0, 20:1, 22:9, 23:0, 24:0, 25:0, 26:0, 27:0, 28:1, 29:0, 30:9, 31:0, 32:0, 33:0, 34:0, 35:0, 36:0		
How? 2=made belief stronger 1=made belief weaker 0=no effect 9=N/A	01:1, 06:0, 11:9, 12:9, 13:9, 14:9, 19:9, 20:2, 22:9, 23:0, 24:9, 25:9, 26:9, 27:0, 28:1, 29:0, 30:9, 31:0, 32:0, 33:0, 34:0, 35:0, 36:0		
Did what they say affect how you felt? 1=yes 0=no 9=N/A	01:1, 05:1, 06:1, 11:9, 12:1, 13:9, 14:0, 19:1, 20:1, 22:9, 23:1, 24:0, 25:0, 26:1, 27:1, 28:1, 29:0, 30:9, 31:1, 32:1, 33:1, 34:0, 35:1, 36:0		
How? 1=felt better 0=felt worse 9=N/A	01:0, 05:0, 06:0, 11:9, 12:1, 13:9, 14:9, 19:1, 22:9, 23:2, 24:9, 25:9, 26:9, 27:0, 28:1, 29:0, 30:9, 31:1, 32:1, 33:1, 34:0, 35:1, 36:0		
Did it affect anything that you did? 1=Yes 0=No 9=N/A	01:1, 05:1, 06:0, 11:9, 12:0, 13:9, 14:0, 19:0, 20:0, 22:9, 23:0, 24:0, 25:0, 26:0, 27:0, 28:0, 29:0, 30:9, 31:0, 32:0, 33:0, 34:0, 35:0, 36:0		
How?	01:1, 05: 0, 11:9,		

1=behaviour changed 0=behaviour didn't change 9=N/A	12:9, 13:9, 14:9, 19:9, 20:9, 22:9, 23:9, 24:9, 25:9, 26:9, 27:0, 28:0, 29:0, 30:9, 31:0, 32:0, 33:0, 34:0, 35:0, 36:0		
Researcher obs: Elated 2=made worse 1=made better 0=no effect 9=NA/missing	01:0, 06:0, 11:9, 12:2, 13:9, 14:0, 19:0, 20:0, 22:9, 23:9, 24:0, 25:0, 26:0, 27:9, 28:0, 29:0, 30:9, 31:0, 32:0, 33:0, 34:0, 35:0, 36:9		
Unhappy/Miserable/ Depressed 2=made worse 1=made better 0=no effect 9=NA/missing	01:0, 05:2, 06:2, 11:9, 12:9, 13:9, 14:0, 19:9, 20:9, 22:9, 23:9, 24:0, 25:0, 26:0, 27:9, 28:0, 29:0, 30:9, 31:0, 32:0, 33:0, 34:0, 35:0, 36:9		
Terrified/ frightened 2=made worse 1=made better 0=no effect 9=NA/missing	01:0, 05:0, 06:0, 11:9, 12:0, 13:9, 14:0, 19:9, 20:9, 22:9, 23:9, 24:0, 25:0, 26:0, 27:9, 28:0, 29:0, 30:9, 31:0, 32:0, 33:0, 34:0, 35:0, 36:9		
Anxious/tense 2=made worse 1=made better 0=no effect 9=NA/missing	01:0, 05:2, 06:2, 11:9, 12:0, 13:9, 14:0, 19:9, 20:9, 22:9, 23:9, 24:0, 25:0, 26:0, 27:9, 28:0, 29:0, 30:9, 31:0, 32:0, 33:0, 34:0, 35:0, 36:2		
Angry? 2=made worse 1=made better 0=no effect 9=NA/missing	01:0, 05:0, 06:0, 11:9, 12:0, 13:9, 14:0, 19:9, 20:9, 22:9, 23:9, 24:0, 25:0, 26:0, 27:2, 28:0, 29:0, 30:9, 31:0, 32:0, 33:0, 34:0, 35:0, 36:2		
Rate preoccupation with beliefs at time of interview	01:2, 02:2, 03:1, 04:1, 05:2, 06:2,	01:2, 05:2, 10:2, 12:1,	01:2, 02:2, 04:0, 05:1,



2=delusion takes up most of time/can discuss nothing else 1=can turn attention to things other than delusion 0=none/thinks of past delusion sometimes	07:2, 08:2, 09:2, 10:2, 11:2, 12:2, 13:1, 14:2, 16:1, 17:2, 18:2, 19:2, 20:2, 21:2, 22:9, 23:1, 24:2, 25:0, 26:2, 27:2, 28:0, 29:1, 30:0, 31:2, 32:1, 33:2, 34:2, 35:2, 36:1	16:1, 17:2, 26:2, 28:0, 31:DK	06:1, 07:1, 08:2, 09:1, 12:DK, 13:0, 14:2, 17:DK, 20:1, 26:0, 27:2, 30:DK, 31:2, 32:DK, 33:1, 36:1
Rate systemisation of belief at time of interview 2=interprets all experiences in delusion terms 1=delusion not elaborated into general system/some elaboration but some experiences not affected 0=none	01:1, 02:1, 03:1, 04:1, 05:2, 06:2, 07:2, 08:2, 09:1, 10:2, 11:1, 12:2, 13:1, 14:1, 16:1, 17:2, 18:1, 19:1, 20:2, 21:1, 22:9, 23:1, 24:1, 25:1, 26:2, 27:2, 28:9, 29:1, 30:1, 31:2, 32:1, 33:2, 34:2, 35:1, 36:1	01:1, 05:2, 10:2, 12:1, 16:1, 17:1, 26:2, 28:9, 31:DK	01:2, 02:1, 04:0, 05:1, 06:1, 07:1, 08:1, 09:1, 12:DK, 13:1, 14:1, 17:1, 20:1, 26:1, 27:1, 30:DK, 31:0, 32:DK, 33:1, 36:1
Uniqueness 2=accepts uniqueness of belief 1=accepts others don't openly share belief 0=belief shared by many others	01:2, 02:0, 03:1, 04:2, 05:1, 06:1, 07:2, 08:0, 09:1, 10:1, 11:1, 12:1, 13:2, 14:2, 16:0, 17:1, 18:1, 19:1, 20:DK, 21:1, 22:9, 23:2, 24:2, 25:2, 26:2, 27:DK, 28:1, 29:2, 30:2, 31:2, 32:2, 33:1, 34:1, 35:2, 36:0	01:0, 05:0, 10:0, 12:2, 16:0, 17:0, 26:2, 28:0, 31:DK	01:2, 02:1, 04:2, 05:2, 06:0, 07:2, 08:1, 09:0, 12:2, 13:2, 14:2, 17:0, 20:2, 26:1, 27:2, 30:0, 31:1, 32:2, 33:0, 36:2
Evidence 2=able to outline evidence and accept this as logically possible 1=able to outline evidence but can't accept possibility 0=unable to outline evidence to contradict belief	01:1, 02:0, 03:2, 04:1, 05:2, 06:0, 07:0, 08:0, 09:0, 10:0, 11:0, 12:0, 13:1, 14:1, 16:1, 17:0, 18:1, 19:0, 20:0, 21:0, 22:9, 23:2, 24:0, 25:2, 26:2, 27:0, 28:2, 29:1, 30:0, 31:0, 32:2, 33:0, 34:1, 35:0, 36:0	01:0, 05:2, 10:2, 12:2, 16:2, 17:0, 26:1, 28:0, 31:2	01:2, 02:0, 04:2, 05:0, 06:0, 07:2, 08:0, 09:0, 12:0, 13:2, 14:0, 17:2, 20:0, 26:1, 27:2, 30:1, 31:0, 32:2, 33:1, 36:0
Treatment (1) 0=accepts need to see a psychiatrist 1=no need to see a psychiatrist but will see one if asked 2=no need to see a psychiatrist and	01:2, 02:0, 03:1, 04:0, 05:1, 06:0, 07:1, 08:2, 09:2, 10:2, 11:2, 12:0,	01:0, 05:0, 10:1, 12:1, 16:0, 17:0, 26:0, 28:0, 31:9	01:0, 02:0, 04:0, 05:1, 06:1, 07:1, 08:1, 09:1,

only sees on under duress	13:1, 14:2, 16:1, 17:2, 18:0, 19:2, 20:0, 21:1, 22:9, 23:1, 24:1, 25:0, 26:2, 27:0, 28:1, 29:2, 30:0, 31:2, 32:0, 33:1, 34:2, 35:1, 36:2		12:0, 13:0, 14:1, 17:1, 20:1, 26:0, 27:0, 30:0, 31:0, 32:0, 33:0, 36:2
Treatment (2) 0=accepts need for drug treatment 1=no need for drugs but will accept when offered 2=won't accept medication 9=no drug prescribed	01:1, 02:0, 04:1, 05:1, 06:0, 07:1, 08:2, 09:1, 10:2, 11:2, 12:1, 13:1, 14:1, 16:0, 17:1, 18:0, 19:2, 20:0, 21:1, 22:9, 23:1, 24:1, 25:1, 26:2, 27:0, 28:1, 29:1, 30:0, 31:1, 32:0, 33:1, 34:1, 35:1, 36:9	01:0, 05:0, 10:0, 12:0, 16:0, 17:0, 26:9, 28:0, 31:9	01:1, 02:0, 04:0, 05:1, 06:1, 07:0, 08:1, 09:1, 12:0, 13:0, 14:1, 17:0, 20:1, 26:1, 27:0, 30:0, 31:0, 32:0, 33:0, 36:0
Self protection 0=refuses to discuss beliefs 1=discusses beliefs only under direct questioning 2=eager to discuss beliefs with all	01:2, 02:1, 03:0, 04:1, 05:1, 06:2, 07:1, 08:0, 09:0, 10:1, 11:0, 12:2, 13:1, 14:2, 16:1, 17:1, 18:1, 19:1, 20:2, 21:1, 22:9, 23:2, 24:1, 25:1, 26:1, 27:1, 28:1, 29:1, 30:1, 31:1, 32:1, 33:1, 34:1, 35:1, 36:1	01:1, 05:1, 10:2, 12:2, 16:1, 17:2, 26:9, 28:2, 31:9	01:2, 02:1, 04:1, 05:1, 06:2, 07:2, 08:1, 09:1, 12:2, 13:2, 14:1, 17:2, 20:1, 26:1, 27:1, 30:1, 31:2, 32:2, 33:2, 36:1
Illness 0=accepts mental illness which includes delusional belief 1=accepts mental illness but does not include delusional belief 2=not ill; belief sound.	01:2, 02:2, 03:2, 04:2, 05:2, 06:2, 07:1, 08:2, 09:2, 10:2, 11:2, 12:2, 13:1, 14:2, 16:1, 17:2, 18:1, 19:DK, 20:1, 21:2, 22:9, 23:0, 24:2, 25:1, 26:2, 27:0, 28:2, 29:2, 30:0, 31:2, 32:0, 33:2, 34:2, 35:2, 36:2	01:0, 05:1, 10:0, 12:1, 16:0, 17:2, 26:0, 28:0, 31:2	01:0, 02:0, 04:1, 05:0, 06:1, 07:0, 08:2, 09:2, 12:1, 13:0, 14:2, 17:DK, 20:0, 26:1, 27:0, 30:1, 31:2, 32:0, 33:1, 36:2
Moral 0=Accepts that behaviour or act was wrong, and feels remorse. 1=Accepts that behaviour or act was wrong, but feels justified. 2=Denies behaviour or act was	01:9, 02:9, 03:9, 04:9, 05:9, 06:9, 07:9, 08:9, 09:2, 10:9, 11:9, 12:9, 13:9, 14:9, 16:2,	01:9, 05:2, 10:9, 12:9, 16:9, 17:9, 26:1, 28:1, 31:0	01:9, 02:9, 04:9, 05:9, 06:9, 07:9, 08:9, 09:2, 12:9, 13:9,

wrong. 9=Not applicable/missing	17:2, 18:9, 19:9, 20:9, 21:9, 22:9, 23:9, 24:9, 25:9, 26:1, 27:0, 28:0, 29:9, 30:9, 31:0, 32:0, 33:0, 34:1, 35:0, 36:9		14:9, 17:2, 20:9, 26:9, 27:0, 30:9, 31:2, 32:2, 33:0, 36:9
Legal 0=Accepts illegality and now believes that should not have broken the law. 1=Accepts illegality but feels justified in breaking the law. 2=Does not consider the law to be relevant / denies illegality 9=Not applicable/missing	01:9, 02:9, 03:9, 04:9, 05:9, 06:9, 07:9, 08:9, 09:2, 10:9, 11:9, 12:9, 13:9, 14:9, 16:2, 17:2, 18:9, 19:9, 20:9, 21:9, 22:9, 23:9, 24:9, 25:9, 26:2, 27:0, 28:2, 29:9, 30:9, 31:0, 32:0, 33:0, 34:2, 35:0, 36:9	01:9, 05:2, 10:9, 12:9, 16:9, 17:9, 26:9, 28:0, 31:0	01:9, 02:9, 04:9, 05:9, 06:9, 07:9, 08:9, 09:2, 12:9, 13:9, 14:9, 17:9, 20:9, 26:9, 27:0, 30:9, 31:1, 32:1, 33:0, 36:9
Risk 0=Recognises risk, and now feels the risk was not worth it 1=Recognises risk, but feels risk was worth it 2=Risk irrelevant, or does recognise any risk 9=Not applicable/missing	01:9, 02:9, 03:9, 04:9, 05:9, 06:9, 07:9, 08:9, 09:2, 10:9, 11:9, 12:9, 13:9, 14:9, 16:2, 17:2, 18:9, 19:9, 20:9, 21:9, 22:9, 23:9, 24:9, 25:9, 26:1, 27:0, 28:0, 29:9, 30:9, 31:0, 32:0, 33:0, 34:2, 35:0, 36:9	01:9, 05:2, 10:9, 12:9, 16:9, 17:9, 26:9, 28:0, 31:0	01:9, 02:9, 04:9, 05:9, 06:9, 07:9, 08:9, 09:2, 12:9, 13:9, 14:9, 17:1, 20:9, 26:9, 27:0, 30:9, 31:2, 32:0, 33:0, 36:9
Reaction of others 0=Understands the reactions of others and accepts these are reasonable 1=Accepts the reactions of others but cannot agree with them 2=Cannot understand why others reacted to behaviour as they did 9=Not applicable/missing	01:9, 02:9, 03:9, 04:9, 05:9, 06:9, 07:9, 08:9, 09:9, 10:9, 11:9, 12:9, 13:9, 14:9, 16:1, 17:2, 18:9, 19:9, 20:9, 21:9, 22:9, 23:9, 24:9, 25:9, 26:2, 27:9, 28:1, 29:9, 30:9, 31:2, 32:0, 33:0, 34:2, 35:0, 36:9	01:9, 05:2, 10:9, 12:9, 16:9, 17:9, 26:9, 28:0, 31:1	01:9, 02:9, 04:9, 05:9, 06:9, 07:9, 08:9, 09:2, 12:9, 13:9, 14:9, 17:2, 20:9, 26:9, 27:0, 30:9, 31:2, 32:1, 33:0, 36:9

**Appendix 28:** Comparison table of delusion type ( derived by MADS free narrative description of patient's most important belief) between patients, relatives and staff

Triads	Patient	Delusion	Delusion type	SO	Delusion	Delusion Type	Staff	Delusion	Delusion type
	025	That I had halitosis and perhaps odours in other ways (not now)	Hypochondrial	CA001			CA001		
	026	Devil was getting the better of him because he was worshipping God and thought he should worship Devil. He can feel the Devil (spiritually) taking over the power of his spirit. The overtaking of the world by the Devil is leading to the end of the world in 2012.	Religious and control	CA002	In more recent times he feels that he has known a penance. He believes in God and the Holy Spirit – he believes that the way he suffers is in parallel with Jesus suffering. He said he feels like he's been crucified. He was trying to find an answer for why he felt like he did.	Religious	CA002	This is quite hard with [P2]. He has strong religious beliefs. He wants to read Devil's bible to get answers. He believes he's being pulled down by God and Devil.	Religious

	027	The Devil and God talk to him. Devil puts thoughts in his mind to hurt others, sometimes God's voice tells him not to.	Religious and control	CA003			CA003	He believes that the Devil talks to him and asks him to harm other. He sees big ugly men dancing.	Religious
	028	"James was going to attack me and he had it all planned out. Beat me up when he sees me in front of all his friends". Developed a systemised paranoid belief regarding one of his acquaintances (that he would attack him). Still believes that the person is out to get him.	Persecutory	CA004 a	He's convinced of what they done to him and what his girlfriend done and putting in his brainbox. When this started he was living in our house being on his own, but he was doting on it and went over the top.	Persecutory	CA004		
	029	How to produce aquatic eqtorial fuel which will be equally as good as crude oil from the sun directly. I know how to get rid of lying from the human race – by investing in personal social	Grandiose	CA005			CA005		

		hygiene and problem solving. I have various attractive attributes including physical attributes and great sexual proven to give pleasure to young ladies (a 56 year old looking older for age, unattractive physically and not in good self hygiene). I can make unusual machines by reasoning.							
	030	The gypsies are following me, by hiding in trees using camouflage. Don't know why.	Persecutory	CA006			CA006	He believes that people are following him. He is paranoid about people trying to get him and attack him. They are monitoring his whereabouts. Hear voices of people talking about him.	Persecutory
	031	Hunted and persecuted by the secret police, made me commit several murders. Tortured	Persecutory	CA007	Paranoid, that's all we know really, it's difficult for the family not knowing. He thinks this person done something,	Persecutory	CA007	<b>CA007</b> – He believes that he himself and his family had been raped and tortured	Persecutory

		me and my parents. Pact of the government; now John Patten (son of Duke of Edinburgh), John Redwood (Tory MP), Michael (resigned from politics, now on TV). Labour – Tony Blair, Alistair Darling, Jack Straw. Got gang-raped by Tory people.			not violent until this incident			by secret police and political parties. He is being forced by secret police to participate in crimes. He believes that he was asked by secret police to throw a bomb and 13 people were killed in bomb explosion.	
	032	Controlled and tormented by the Demons – making me upset, derogatory voices; one male and one female. Female voice is nasty, male voice is alright.	Delusion of control and religious	CA008			CA008	CA008 – Difficult to say. He reports fuzzy feelings inside his head. He says that powers are pushed inside his head, these powers are invasive in nature and he feels that he is being controlled by these voices.	Delusion of control
	033	Paranoia – people are talking about me. Brother can talk to him in a telepathic way.	Delusion of control and persecution	CA009			CA009	CA009 – He believes that his brother can communicate with him; he passes	Delusion of control and probably persecution

		People can input thoughts into his mind and uses to make him do bad things						derogatory remarks about him and asks him to have sex with his daughter. He can have telepathic communication with his brother.	
	34	Sense murder network around myself. The state and authorities have covered it up due to their implications. Utilised psychiatry to shut me up and silence and (affect?) me as a witness. (Imply?) questionable in legal aspects (as? And?) they cannot (trial to ...) murder and have yet done so. Yet they have sectioned me. ... my (unseen?) status. Police of South Wales are liable for murder and unlawful acts. Police murdered my daughter and	Persecutory	CA010			CA010		



		<p>imminently killed other members of my family. This is a complicated scenario.</p> <p>Conducted my sectioning in a seemingly (?) manner (?)</p>							
	35	<p>I believe my religious experience. God and Satan are present in my head and are talking to me, telling me of my special mission. Satan – you are in(?). Women hate you. God – Only for a certain time and it will pass. My work used to come out of the darkness</p>	Religious	CA011			CA011		

	001	<b>001-</b> I feel I am attached towards someone called Y who I never saw or met. I believe that X (ward manager) is the same person I used to love. I rang Y one day and his wife answered, she became crazy and sent someone to upset me. She called the police, then police started following me. I believe my husband has an affair with other women, because he is buying new clothes and shaving to be more handsome.	Morbid jealousy		<b>0001-</b> Major delusion- her husband is having an extra marital affair, she causes great embarrassment by calling people at his work and asking questions about his love life, this is interrelated to the belief that she has to see a guy from her past.	Morbid jealousy		<b>001.1-</b> She believes that her husband's having an affair with various women and staff, body language is how she knows about it.  <b>001.2-</b> She believe that she's having a relationship with a man named Hugh who she never met and then believes that Hugh is with one of the nurses on the ward.	Morbid jealousy
	002	<b>002-</b> I am evil doctor and empty of life because I don't respond to affection. I am evil because I don't respond to people trying to help me. I don't deserve even the room I am	Hypochondriacal					<b>002-</b> He believes he's the devil and a bad person.	Religious

		staying in now. I don't take shower or bath but cant explain why doctor. All I can say is I feel dirty I am not clean.							
	003	<b>003-</b> My neighbour can hear my thought's through the walls. They (family, especially the woman) installed hearing instruments in the walls so they can read my mind or tell other neighbours about it. That makes me very anxious with thoughts of ending my life.	Persecutory						
	004	<b>004-</b> There are some people who want to embarrass me, they make me angry. I don't know	Persecutory					<b>004-</b> Something bad is going to happen to him but he hasn't identified anybody.	Persecutory

		who they are. They make me think everyone can hear what I am thinking of.							
	005	<b>005-</b> People from the royal mail want to kill me through my best friend, but because my best friend is handicapped he asked my brother inlaw (who is also my neighbour) to kill me by shooting me with a gun. It is so complicated, my brother in law is killed and murdered in the bible, he come and go.	Persecutory		<b>0005</b> – He has had other lives, he has had wife and children. He has names for them, wife=Rebecca, children=two, sex not known.	Other paranormal/religious		<b>005.1-</b> He believes that he has to kill his brother-in-law to protect his family.	Persecutory
	006	<b>006-</b> My brother stole my money, a lot of money; more than £100,000 and he bought a brand new car for him and his wife from my money. He wants me to be crazy.	Persecutory					<b>006.1-</b> He believes his brother-in-law is ripping him off and taking money from him.	Persecutory

	007	<b>007-</b> Some people out there have taken my semen, and left me with no semen. My crystal pipe (penis) is not working and became too small when I came to the real life. I haven't released for last 2 weeks, when I release I become alien, my face looks different in the mirror.	Hypochondriacal					<b>007.1-</b> The sputum was taken from him and he doesn't know who or why or where.	Hypochondriacal
	008	<b>008-</b> I believe Jesus died for me, he sacrificed his life for the sake of me. I am pregnant because of Jesus, he has chosen me to be his child.  NB: the patient changed her mind part way through	Religious					<b>008.1-</b> She thinks that Jesus is talking to her mainly through the TV, rest of the time is advert love and relationships 'cause she thinks she is young, she needs a boyfriend as Jesus told her.	Religious

		the MADS and said she doesn't talk with anyone about her beliefs. She said she is not feeling well now and doesn't want to continue/talk about this. She said "it's affecting my health, my health is deteriorating".							
	009	<b>009-</b> I have healing powers and I can cure ill people. I cured many patients by touching my hand into my heart. I have been chosen by God I want to help people. I am virgin Mary and I am pregnant now.	Grandiose and religious					<b>009.1-</b> She believes she is in a relationship with Matt Bross, he is going to come and pick her up at times.	Erotomania
	010	<b>010-</b> there is a conspiracy by doctors because they are after by WBC, they give me clozapine, they want to continue their dodgy experiment on me.	Persecutory		<b>0010</b> – He is a Messiah and has been sent to earth to save the world from evil.	Grandiose And/or religious		<b>0010-</b> That he has a wife who he met in his dreams, she lives in America, he has a ring she bought him and believes she is coming to see him soon and they are	? Erotomantic ? Grandiose

		I have been monitored for more than one race of will? There are 7 thousand doctors against me who are going to release the beast next week.						going to be together.	
	011	<b>011-</b> The patient has many odd delusional beliefs- talks about psychology, supernatural, wisdom of others. Psychiatric medications are poisonous and toxic, they damage my brain. I am forced to take them, I am being poisoned.	Persecutory						
	012	<b>012-</b> I am the second richest man in Cardiff (David Morgan is first). I won the lottery and I will live forever, I will marry tomorrow and you will see	Grandiose		<b>0012</b> – He had won a lottery, a huge amount of money. Convinced won the lotto lottery. Refuses to discuss it in detail. Always keeps on asking if lottery people have been in touch to	Grandiose		<b>0012.1-</b> He believes that he's won the lottery and a TV crew are coming to interview him about the money and he's going to marry one	Grandiose

		that in the press. I won £265 million and I will live forever.			hand over the money.			person from the TV programme (presenter).	
	013	<b>013-</b> I am the modern day Christ to save the world somehow, but it means that I have to sacrifice my life just like what Jesus did the first time for the sins of the world.	Religious					<b>0013.1</b> – He believes that he is Jesus and thinks other people act like biblical ???	Religious
	014	<b>014-</b> I stopped taking clozapine for my illness because I was healed by God, God healed my illness I am blessed by God. I am different than others, I don't believe in doctors and their medications. I will be punished by God for visiting prostitutes and using drugs.	Religious					<b>0014.1-</b> He has been healed, has no psychotic illness, he has sinned against GOD and the holy spirit by sleeping with prostitutes and feels guilty.	Religious
	015	<b>015-</b> Some people want to do an	Persecutory					<b>0015.1-</b> There's a conspiracy and	Persecutory



		experiment on me and the leader is Gordon Brown. They tell me you are a puppet they also tell me to kill myself.						Gordon Brown is the head and people around are part of it and they experiment on her.	
	016	<b>016-</b> Dr X (consultant) doesn't like me, he tries to poison me through the staff. HE says ignore her she has P.D., he and the staff look at me as a piece of crap. He doesn't believe me. The staff nurse wants to bully me and poison me.	Persecutory		<b>0016</b> – Hears a number of voices telling her to kill other people/harm others. Believe certain people talk to her even when not around because they hate her.	Persecutory			
	017	<b>017-</b> I am a superhero, I have 6 senses. God chose me for being king and gave me all sorts of talents. I am a professor, a physicist, preacher, SAS soldier. With me I got a diploma in body, mind and spirit. I did	Grandiose		<b>0017</b> – He has had an encounter with God. God gave him light and he was saved by God's face, he met God in person.	Religious		0017.1 He believes he is in the SAS and that he has a doctorate in medicine.	Grandiose

		microbiology and biochemistry aswel.							
	018	<b>018-</b> I have all the power to change the weather. I have the power of God and may be Jesus Christ. I have psychic and therapeutic power to help my family and patients. The big bang theory just set it off. I send me back to hell and ruin my family.	Grandiose						
	019	<b>019-</b> I am queen Elizabeth, I am Elizabeth the 3 <sup>rd</sup> and my father is George the 7 <sup>th</sup> , people ask for my advice form all over the world. I advise India and Pakistan to stop fighting and they stopped. I have healing power in my hands and can cure patients with HIV and	Grandiose						

		cancer.							
	020	<b>020-</b> I am married to Michael Jackson but it is not legal. He kept his house in Neverland for me. We are married by soul mates by open hearts but we are not doing miracles. He composed songs for me, he calls me you're my dark child.	<a href="#">Erotomania</a>					<b>0020-</b> She continues to talk about Gordon Brown being out to get her (about the voices screaming at her not to eat).	<a href="#">Persecutory</a>
	021	<b>021-</b> The world is unsafe, very dangerous to the public now. The police are following me now, there is no offence but people around are bastards and terrible. I will go to heaven and escape the police and meet my father there. God is	<a href="#">Persecutory</a>						

		powerful and will help me there safe.							
	022	<b>022-</b> my neighbour interferes with my mind, he frightens me. Dr smith read my mind and knows that X (neighbour) is feeling my body. He is locked up now. I don't say to anyone and never talked about this with Dr Smith. HE put pink in my head and I felt petrified, touch my body and boobs, I feel terrified. I don't want to talk Dr please. It's horrible, I am not clean, I feel dirty.	Persecutory						
	038	<b>038</b> – "I am a mind reader, I can read people's minds including drug dealer. I can see how a fast car should be designed in my mind and draw it on paper	Grandiose						

		and send it off to a manufacturer. The voices are from the medications”							
	039	<b>039</b> – “My wife is cheating on me, she is doing it with everyone, particularly the neighbour”	Morbid jealousy						
	036	<b>LCH001</b> - He believed and actually is convinced that some of police wanted him to be locked in a place because he gave a name of someone involved with illegal business with the police and then he was accused without evidence and then they think you are psychotic because he doesn't forget about it.	Persecutory					<b>LCH001-</b> Believed the police had set him up. Accused of things he didn't do.	Persecutory

**Appendix 29:** Frequency of the most important delusion type derived by CPRS

Research no.	29. Feeling controlled	30. Disrupted thoughts	31. Ideas of persecution	32. Ideas of grandeur	33. Delusional mood	34. Ecstatic experiences	35. Morbid jealousy	36. Other delusions
1.1	0	2	1	0	0	1	2	3
2	0	999	2	0	0	1	1	999
3	0	2	2	0	0	0	1	0
4	2	2	2	0	0	0	0	0
5.1	3	2	3	0	0	0	0	1
6.1	0	2	3	0	1	0	0	2
7.1	3	2	3	0	0	0	0	2
8	2	2	1	0	0	1	0	0
9	2	2	2	2	0	2	1	1
10	1	1	3	0	2	1	999	0
11	0	0	2	0	2	2	0	0
12	2	1	0	2	0	2	0	0
13	2	1	999	2	0	2	0	0
14.1	0	1	0	2	0	1	0	0
15	3	2	3	0	0	0	0	2
16	3	3	3	0	0	0	1	1
17	0	2	1	3	0	2	1	0
18	2	2	1	0	0	2	0	0
19	999	2	1	2	0	1	0	0

20	1	0	2	2	0	2	1	2
21	0	1	3	0	1	2	1	0
22	1	3	2	0	0	1	0	0
23	0	0	1	3	0	0	0	0
24	0	1	0	1	0	0	3	0
25	0	0	0	0	0	0	0	0
26	0	1	0	0	0	0	0	999
27	2	0	2	0	0	0	0	2
28.1	0	1	2	0	0	0	0	0
29	0	0	1	2	0	1	0	2
30	0	0	2	0	0	0	0	0
31	0	0	3	0	0	0	0	3
32	0	2	0	0	0	0	0	0
33	0	2	2	0	1	0	0	0
34	0	0	0	0	0	0	0	3
35	0	0	0	3	0	0	0	3
36	0	0	3	0	0	0	0	0

**Appendix 30:** Table of the 'coded' delusion type and its frequency (derived by CPRS)

Research no.	Delusion type	Frequency
001.1	001.1 jealousy+other	Persecutory=20
002	002 persecutory	Control=11
003	003 persecutory	Grandeur=10
004	004 control+perscutory	Ecstasy=8
005.1	005.1 control+persecutory	Other=8
006.1	006.1 persecutory+other	Jealousy=2
007.1	007.1 control+persecutory+other	Autochthonous=2
008	008 control	
009	009 control+persecutory+grandeur+ecstasy	
010	010 persecutory+autochthonous	
011	011 persecutory+autochthonous	
012	012 control, grandeur, ecstasy	
013	013 control, grandeur, ecstasy	
014.1	014.1 grandeur	
015	015 control, persecutory, other	
016	Control+persecutory	
017	Grandeur + ecstasy	
018	Controlled+ecstasy	
019	Grandeur	
020	Persecutory+grandeur+ecstasy	
021	Persecutory +ecstasy	
022	Persecutory	
023	Grandeur	
024	Jealousy	
025	-	
026	-	
027	Control+persecutory+ other	
028.1	Persecutory	
029	Grandeur+other	
030	Persecutory	
031	Persecutory+other	
032	-	
033	Persecutory	
034	-	
035	Grandeur++other	
036	Persecutory	



**Appendix 31:** Outgoing and Withdrawal behaviour driven by the patient's most important delusional belief: Questions taken from the (MADS).

**Outgoing actions:**

If any of the following outgoing actions occurred more than once a week, that patient was given a score of 1. If not they were given a score of zero.

1. Have you told anyone about X?
2. Have you written to anyone?
3. Have you tried to stop X from happening?
4. Have you tried to protect yourself in any way? (Specify)
5. Does X make you lose your temper?
6. Have you broken anything because of this?
7. Have you felt like hitting someone because of it?
8. Have you hit anyone because of it?
9. Have you tried to harm yourself or harmed yourself because of X?
10. Have you tried to move or leave your house (area) because of X?

**Withdrawal actions:**

If any of the following withdrawal actions occurred more than once a week

1. Has X stopped you from doing things you would normally have done?
2. Has X stopped you from meeting friends, other patients, staff, relatives or partner?
3. Has X stopped you from watching T.V. or listening to the radio or reading?
4. Has X stopped you from eating/drinking anything?
5. Has X stopped you from using transport?
6. Has X stopped you from going to...Paid work? Other activities (If yes, which one? ie, Cooking, Gardening, Pottery) Social club, café, shop?

7. Has X stopped you from taking medication?
8. Has X stopped you from going to your hospital/your doctor on an outpatient basis?
9. Is there anything else which X has stopped you from doing? (record verbatim)
10. Is there at least one thing which X has stopped you from doing? (record verbatim).