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**Evaluation of advance statements in psychiatric  
care**

**by**

**Alexia Papageorgiou**

**BA MSc**

**Thesis submitted for Degree of Doctor of  
Philosophy  
University of London  
2006**

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## **Abstract**

### **Background**

An advance statement in psychiatric care is a statement of a person's preferences for treatment, should he or she lose capacity to make treatment decisions in the future. The underlying principle for implementing these instruments is the promotion of patients' self-determination and autonomy.

### **Objective**

To evaluate whether use of advance statements by patients with severe mental illness leads to lower rates of compulsory readmission to hospital.

### **Design**

Randomised controlled trial.

### **Setting**

Two inner city psychiatric hospitals in North London.

### **Participants**

One hundred and fifty six in-patients about to be discharged from compulsory treatment under the Mental Health Act were recruited. To be included, participants had to be 18 years old and over, with mental capacity, able to read and write English and on section 2, 3 or 4 of the Mental Health Act.

### **Intervention**

The preference for care group and the control group both received standard psychiatric care plus a number of standardised questionnaires at baseline and a year after discharge from section. In addition to that the preference for care group received the psychiatric advance statement at baseline.

### **Outcome measures**

The main outcome measure was the rate of compulsory re-admission. Other outcome measures involved: the patients' self-efficacy and satisfaction with psychiatric services, their mental health status assessment, their views about the usefulness of the advance statements, assessment of the content of the statement and the views of mental health professionals in relation to the usefulness of the statement.

### **Results**

Fifteen patients (19%) in the intervention group and 16 (21%) in the control group were readmitted compulsorily within 1 year of discharge. There was no difference

in the numbers of compulsory readmissions, numbers of patients readmitted voluntarily, self-efficacy or satisfaction with psychiatric services. Patients with severe and enduring mental health problems were capable of drawing up advance statements with their views in relation to signs of lapses and relapses, and their preferences and refusals on certain aspects of their treatment and needs whilst hospitalised. Patients did not use the advance statements as an opportunity to refuse all subsequent treatment. Although 40% of patients did not find the advance statements useful, this may have occurred because the professionals involved in their care did not refer to or take account of them. Most mental health professionals who returned questionnaires did not find the advance statements useful in the management of the patients.

### **Conclusion**

Users' advance statements for psychiatric care had little observable impact on the outcome of care at twelve months. Even if rates of compulsory treatment were not affected, one cannot rule out possible beneficial effects such as improvement of therapeutic alliance and communication with mental health professionals. Thus, the impact of advance statements on other aspects of care requires further study.

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## **Conjoint Statement**

My supervisor Professor Michael King developed the original idea, wrote the protocol and obtained ethical approval. I developed the idea about incorporating the psychological construct of self-efficacy and carried out the study including recruitment of patients, data input, analysis and writing up the thesis.

Anis Janmohamed and Jody Raab helped with recruitment and follow-up of participants.

**To my parents Evagelia and Konstadinos**

*Στους γονείς μου Ευαγγελία και Κωνσταντίνος*



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## **Literature search strategy**

We used the OVID versions of the following Databases:

Medline 1966-present

Embase 1980- present

PsycInfo 1887- present

Cinahl 1982- present

We performed searches at the beginning of this project in 1996, then in 2000, 2002, 2004 and the last one in December 2005.

We began our search strategy with three main search terms: advanced directives, mental capacity and self-efficacy. For each concept, we searched using thesaurus terms as well as text words to capture all synonyms. In the first search, advanced directives was combined with mental capacity and this was run against the databases listed above. Four hundred and nine records were retrieved but only 100 of them were relevant. The second search focused on advanced directives and self-efficacy. Forty records were retrieved but only 24 were relevant. A methodological search filter designed to retrieve clinical trials and randomised trials was added to both searches.

## **PART I**

### **INTRODUCTION AND LITERATURE REVIEW**

## **Introduction**

Patients' advance statements for psychiatric care are usually oral or written statements with the patient's specific or general preferences and/or refusals for various psychiatric treatments, executed before they become incompetent. Patient advance statements can only be understood in the context of the development of psychiatric services and the development of patients' autonomy and self-determination in general and mental health services.

### **Autonomy and self-determination in general and mental health care**

According to Feinberg, autonomy has many meanings (1). "It can refer to *capacity* to govern oneself, which of course is a matter of degree; or to the *actual condition* of self-government and its associated virtues (e.g. self-identity, authenticity, self-determination, self-legislation); or to an *ideal of character* derived from that conception; or (on the analogy to a political state) to the *sovereign authority* to govern oneself, which is absolute within one's own moral boundaries (one's 'territory,' 'realm,' 'sphere,' or 'domain')." (p. 28) In this thesis, autonomy and self-determination will be explored in relation to patients' advance statements for psychiatric care. However, in order for these concepts to be understood in the context of psychiatric care, their relation to general health settings has to be outlined first.

Modern medicine has moved a long way from medical paternalism towards practices that take into account patients' individual needs and increase doctor-patient communication. Today we talk about patients' self-determination and autonomy, their right to consent to treatment, their right to refuse treatment and their right to decide about their body after death. National health policies (e.g. The National Service Framework for Mental Health) have been developed to promote and protect these rights. However, the process of shifting the power and control from doctors to patients and towards shared decision making in health care has created a difficult dynamic that is expressed by conflict, uneasiness and discomfort between the two groups in most post-industrial societies. It is common to hear on the news or read in the newspapers stories that exemplify this conflict.

*A woman yesterday told of her horror at discovering that hospital doctors had decided not to resuscitate her. Jill Baker, 67, who has stomach cancer, only found out after she left hospital that the words, "inappropriate for resuscitation", had been written on her hospital notes. Neither she nor her husband had been asked for their views. She said she was "written off" by a doctor who never met her. But today, nine months later, she is enjoying a good quality of life (Guardian, Thursday April 13, 2000).*

Medical law and ethics, a new breed of disciplines in the medical curriculum, have been born out of the need to protect both patients' and doctors' rights. However, the exercise of doctors' paternalism is still evident. Mrs Baker's case is a clear example of how medical practice can undermine patients' self-determination and autonomy in the 21<sup>st</sup> century.

To protect patients' autonomy and self-determination, English law has recognised that a competent patient has the right to refuse treatment, even life sustaining treatment. This has been illustrated in the case of Miss B, a 43- year-old woman who won her high court battle for the right to die peacefully and with dignity (The Guardian, Friday March 22, 2002). Her case, which is described below, is significant, not only because it sets a legal precedent that other patients may wish to follow, but also because it addresses important issues, such as how far the doctor's duty of care extends, assessment of patients' mental capacity and the importance of advance statements (patients' refusals for treatment) in advance care planning.

*Miss B was informed by her doctors, in August 1999, that a malformation of blood vessels in her spinal column could result in severe disability. As a result of that consultation, she wrote out a will stating that she did not wish to receive treatment if she was left suffering from a life threatening condition, permanent mental impairment or unconsciousness. When her condition improved, Miss B left hospital optimistic about her future and eventually returned to work. However, at the beginning of 2001, she began to suffer weakening on the left side of her body and numbness in her legs. In February a massive recurrence of the bleeding left her tetraplegic, with complete paralysis from the neck down. She was transferred to an intensive care unit, where she has been since, entirely dependent on a ventilator. At the time of her transfer she referred the two consultants treating her to her will, which stated that she did not want to be kept alive on a ventilator. But the doctors said her will was not specific enough to authorise them to end treatment. After an operation that relieved her condition, allowing her to move her head and to speak, she again asked for the ventilator to be switched off. By April, Miss B gave formal instructions via her solicitors for her treatment to cease and the hospital responded by calling in two independent psychiatrists to assess her competence to make the decision. Both initially found she did have such a capacity, but then reversed their findings. While this was going on, preparations had been made for the ventilator to be switched off, and Miss B held discussions with one of the doctors, agreeing she should have three days to say goodbye to her friends and family and to finalise her affairs. These preparations were called off when the psychiatrists changed their reports and Miss B was prescribed antidepressants. It was at this time that Miss B did agree she was relieved the ventilator had not been switched off and in May said she would try rehabilitation.*

*But in August Miss B authorised a doctor to reassess her ability to make decisions on her treatment and he found that she was competent. The hospital said it respected her decision, but did not turn off the ventilator. Doctors at the hospital said it would be against their ethics to switch off the machine needed to keep the patient alive (The Guardian, Friday March 22, 2002).*

As Miss B said in reply to the court ruling, “the law on consent to treatment is very clear and this has been a long and unnecessary and personally painful process.” (The Guardian, Friday March 22, 2002)

Could this painful process for Miss B be avoided? What were the factors that hindered the process of honouring her wishes? One factor relates to the clarity of her wishes. Her doctors said her advance statement was not specific enough to authorise them to end treatment. The second factor points in a different direction, that of her mental capacity to make treatment decisions. Psychiatric evaluation on two occasions showed that she was competent to make the decision to refuse but still her wishes were not honoured. Miss B’s example reiterates the complicated nature of our society’s dilemma: honouring patients’ wishes may put doctors and nurses in the position of carrying out euthanasia which is not acceptable to English law and against their duty of care, while disobeying their patients’ wishes may be a case of battery.

If patients with sound mind face difficulties convincing their doctors about their abilities to make treatment decisions, what happens with those who are ascribed the status of a psychotic patient?

Mr C was a patient in Broadmoor, detained under section 3 of the Mental Health Act 1983. He suffered from delusions that some of the Broadmoor staff were torturing him and that he had been a doctor who could cure damaged limbs without resource to amputation. On September 9 1993, the hospital staff noticed he had a swollen leg. The Broadmoor surgeon diagnosed gangrene in the foot and he was transferred to a surgical hospital. The consultant vascular surgeon suggested that Mr C would die imminently if the leg were not amputated below the knee. Mr C refused to allow his leg to be amputated in any circumstances then or at any time in the future. He applied to the High Court for an injunction restraining amputation on that basis. “His competency to consent to treatment was

assessed but no link was found between C's refusal and his persecutory delusions. In addition to that, C was found to be quite content to follow medical advice and to co-operate in treatment appropriately as long as his rejection of amputation was respected." (2) (p. 623) His application to the High Court was successful and he became the first English psychiatric patient detained under a section of the Mental Health Act 1983 to have the right to refuse medical treatment recognised by a court (3).

The case of Mr C pointed to another major shift towards patients' self-determination and autonomy in the complex context of psychiatric care: recognition that detention under the Mental Health Act and a psychiatric diagnosis do not necessarily lead to mental incapacity to make treatment decisions. However, things become more complicated when psychiatric patients refuse hospitalisation and treatment for their psychiatric condition.

In *Rennie v. Klein*, in which a repeatedly admitted patient argued for his right to refuse psychiatric treatment, the District Court in the United States articulated that mental illness was not equivalent to incompetence and that the mentally ill had a right to refuse treatment for the reason of side effects in the absence of an emergency (4). More recently, Nancy Hargrave a patient with history of paranoid schizophrenia and multiple admissions to the Vermont State Hospital, had written a psychiatric advance statement that refused "any and all antipsychotic, neuroleptic, psychotropic, or psychoactive medications" if she became ill and was involuntarily committed (5). The U.S. District Court allowed the advance statement to stand as written even when the patient was involuntarily committed (5).

By citing the above legal cases, I have tried to paint a picture of the difficulties associated with the concept of autonomy and self-determination in the context of general and mental health care. In the pages that follow, I will discuss the complexities underlying these concepts within the context of psychiatry in Britain and the USA, focusing on patients' advance statements for psychiatric care. Most of the academic and legal discussion to date has not been in this area, but on end-of-life decisions.



I will begin with a discussion of psychiatric and medical advance statements and will explore their underlying conceptual basis, their potential value and the difficulties in implementing them. Inherent in psychiatric advance statements' implementation is the concept of mental capacity, which I will explore next. In chapter three, I will discuss the concept of self-efficacy and its relevance to the preference for care study. The final chapter of the literature review will focus on an overview of randomised controlled trials. I will then describe the research I carried out and the findings in relation to psychiatric advance statements. In the final chapters, I will discuss these findings in relation to previous research in the area and the new ways this project has opened in terms of future research and policy making in relation to psychiatric advance statements.

## **CHAPTER 1**

### **PSYCHIATRIC ADVANCE STATEMENTS**

In the following pages, I will first look at the changes in psychiatric services and the advocacy movement that gave rise to psychiatric advance statements, patient autonomy and self-determination in the last half-century. Then I will attempt to unfold the historical development of advance statements before I move on to the legal and philosophical issues underlying the design and implementation of such documents in the context of general medicine and psychiatry. Finally, I will look at the effectiveness of such documents in medicine and psychiatry and the challenges of implementing them in today's NHS.

## **Changes in psychiatric services during the last half-century that led to users' autonomy and self-determination**

Patient advance statements can only be understood in the context of the development of psychiatric services and the development of patients' autonomy and self-determination in general and mental health services. In this part of the thesis, the development of psychiatric services will be explored.

### ***From asylums to community care and treatment***

In the USA, there was a 34% decrease in psychiatric hospitals from 1954 to 1998 while the year-end census of patients between 1954 and 1996 decreased by 89% (6). The decrease in the size of state hospitals was mainly due to reduced inpatient care (e.g. from 44 days median length of stay in 1971 to 26 days in 1975) (6). A similar trend was observed in England. The number of psychiatric beds decreased from 152,000 in 1954 to 39,500 in 1993, a reduction of 74% (7).

The main reasons for the closure of many state hospitals in the seventies involved overcrowding, under-funding and low standards of care (6;8). Muijen (1996) in his chapter on "Scare in the Community", summarises very eloquently the public's feeling of loathing for the rigid care of the mentally ill in state hospitals which ignored human values and were "dominated by a self-satisfied medical model insensitive to patients' experiences." (p.144) Issues such as patient institutionalisation and families' and patients' resistance to discharge led the state hospital managers of that decade to seek integration with community services (e.g. geographical matching of state hospital wards and catchment areas) in the USA (6). In England, the care of acutely mentally ill people was to be provided locally, in district general hospitals while those with long-term psychiatric problems were cared for in rehabilitation hostels in the community which were funded by local authorities (8;9). However, the decrease in hospital beds and the discharge of patients in the community was poorly co-ordinated which led to new problems in the eighties (6;8;9). Patients with severe problems were not admitted due to lack of hospital beds and those still at risk were discharged early (6;8;9). Poor coordination of psychiatric services led to shocking events such as the killing of

Isabel Schwarz a social worker by her former patient Sharon Campbell at Bexley Hospital (8). That event shifted the anger of the public from the hospital staff (who were previously viewed as abusers and oppressors) to the mentally ill people and the inadequacy of community care (6;8). The public's fear that community care was out of control was further reinforced by more publicised scandals committed by mentally ill people in the early nineties (8). "Concerns were repeatedly expressed that the movement towards community care had resulted in excessive burden on carers, an increase in the homeless mentally ill, diversion of the mentally ill into the criminal justice system and a poor quality of life for people released from hospital without adequate further care and support. One recurring theme was that people were 'falling through the cracks'." (10) (p.235) As a consequence, in England, the Royal College of Psychiatrists was asked to produce guidelines on good practice for discharge and aftercare procedures. Statutory revisions of the 1959 and 1983 Mental Health Acts led to the Mental Health (Patients in the Community) Act (8;11). Service evaluation interventions that started in the seventies offered new insights and led to the development of 'case management' and 'assertive community treatment'(6). The aims of case management are "to ensure continuity of care, accessibility to often fragmented and independently managed services, accountability, and efficiency. The core functions usually include: assessing patients' needs; developing a comprehensive care plan; arranging service delivery; monitoring and assessing services; evaluating progress and follow-up. Although the practice of case management varies, two general approaches can be identified. Service 'brokerage' case management sees the 'case manager' as an enabler, systems coordinator, or broker of services. In 'clinical' case management on the other hand, the professional has a direct treatment relationship with the patient, often being personally involved with aspects of the patient's psychological, physical and social care." (7) (p. 364) The new focus on evaluation research including the effectiveness of case management in the eighties did not support simple implementation of case management (12;13) turning the attention of service providers to 'assertive community treatment'. "Assertive community treatment aims to provide a comprehensive care package including treatment and support services via a multidisciplinary team within the community. It includes frequent contacts with patients in the community (often at

home), 24-hour availability, direct responsibility of staff for a broad range of interventions, and low staff/patient ratios.” (7) (p.365)

In summary, the psychiatric services of the 20<sup>th</sup> century were mainly characterised by closure of the asylums and transfer of patients’ care in the community. Apart from acute inpatient care that happens in general and state psychiatric hospitals, at present, community care is mainly delivered by multidisciplinary teams such as ‘assertive outreach teams’.

### ***Consumer advocacy and empowerment***

Along with the changes in the organisation and delivery of psychiatric services, consumer- advocacy and empowerment has been growing fast and strong.

At the beginning of 20<sup>th</sup> century, people with serious mental illness were usually isolated from society by being locked in state psychiatric hospitals (14). Those with less severe mental illness could probably try to live a 'normal' life in the community but hide their disability because of the stigma associated with it (15). In his historical overview of the consumer-advocacy movement, Frederick Frese (1998) a clinical psychologist diagnosed with paranoid schizophrenia writes: "as long as persons with schizophrenia and their family members were too ashamed to openly identify themselves, practically speaking, no one who had any personal experience with these disorders could give any effective feedback concerning their satisfaction, or lack thereof, with the mental-health services." (15) (p.236) With the closure of many public psychiatric hospitals and the exodus of patients in the community, a small number of ex-inpatients who recovered sufficiently started gathering together and sharing their views (15). "Many of these former patients had been forced into treatment and felt they had been abused during their experience. They believed that they had not been given respect or dignity while they were hospitalised. Many became angry at the psychiatric establishment, and looked for examples of psychiatry being portrayed as uncaring and oppressive."(15) (p.237) These groups viewed psychiatrists as oppressors, they identified themselves with members of other traditionally excluded and oppressed racial, religious and ethnic groups and gave themselves names such as the 'Mental Patients' Liberation Project in New York' (15). In the USA, the government started to take notice of these groups and in 1976 established the President's Commission on Mental Health. Furthermore, in 1985, consumer advocates were funded by the federal government's Community Support Program to attend national conferences (15).

In the UK, the Mental Patients' Union and the 'anti-psychiatry movement' in the seventies, encouraged a number of ex-inpatients to get involved in groups such as the British Network for Alternatives to Psychiatry and the Campaign Against

Psychiatric Oppression. These individuals went on to organise the first National Mind Annual Conference which took place in 1985 and gave birth to two user/survivor organisations: Nottingham Advocacy Group and Survivors Speak Out (16).

According to Frese (1998), a schism followed those first conferences (15). One group of ex-inpatients opposed forced treatment under any condition and viewed psychiatric treatment and psychiatrists as oppressors. They preferred to call themselves survivors. The other group was more moderate regarding forced treatment and called themselves users or advocates. Szasz (1982) using the term 'psychiatric will', offered a solution to this debate by suggesting to users to document their preferences for or against psychiatric treatment and make them known to their care providers (for a detailed definition and explanation of psychiatric wills see the following section). The principles and identities of the above groups have changed over the years in order to reflect the changes in society and psychiatric care (15;16). However, their principles about patient empowerment and improvement of their human rights have grown even stronger and have given rise to the "current, pragmatically-oriented user/survivor organisations." (16) (p. 219) Local service user groups play a very important role in mutual support, combating stigma, helping people to recover and stay out of services, and participating in local service planning and development. Nationally, the most prominent current advocacy issues related to user empowerment, autonomy and self-determination, have been informed consent, involuntary admission, users' participation in research projects and psychiatric advance statements (15).

In summary, during the first half of the 20<sup>th</sup> century doctors had monopoly over the practice of medicine in general and psychiatry in particular. With a change of focus on cost-effective care, politicians and those responsible for financing health care turned to service recipients for input as to what is the best care for them. Through the debates of consumer-advocacy groups psychiatric advance statements have been at the forefront of modern psychiatric care.

## Definition of psychiatric advance statements

Psychiatric advance statements are a person's written or oral preferences for treatment should he or she lose capacity to make such decisions in the future. In the literature, psychiatric advance statements appear under different names.

The oldest definition is that of 'psychiatric will' proposed by Szasz in 1982. His response aimed to provide a solution to the debates among user groups and anti-psychiatry campaigners in relation to involuntary commitment and coercive psychiatry (17). He wrote:

"The imagery of 'sudden madness' or 'acute psychosis' sketched earlier represents the dreaded situation that some persons may want to anticipate and plan for. Since involuntary psychiatric confinement is a tradition-honored custom in modern societies, the situation such persons need to anticipate must be *their own sudden madness managed by others by means of commitment and coerced treatment*. To forestall such an event, we need a mechanism enabling anyone reaching the age of maturity, who so desires, to execute a 'psychiatric will' prohibiting his or her confinement in a mental hospital or his or her involuntary treatment for mental illness. Those failing to execute such a document before an actual encounter with coercive psychiatry would, of course, have the opportunity to do so as soon as they have 'recovered' from their first episode of 'mental illness' or otherwise regained their competence. ....This would leave everyone who has not executed a psychiatric will free from psychiatric coercion, much as we are free, without having to go to such troubles, of theological coercion." (17) (p. 768)

Survivors Speak Out, one of the UK's leading user groups proposed the term 'crisis cards' or 'treatment contracts'(18). These documents are made by the patient and include 'packages of care' that should be used by treatment providers in a crisis. In order to evaluate the effectiveness of 'crisis cards' Sutherby et al (1999) and Henderson et al (2004) borrowed the term 'crisis card' and extended it to 'joint crisis plans' to document patients' choice of information and preferences for care that are drafted in collaboration with their treatment provider (18;19).

Another frequently quoted definition is that of 'Ulysses contract' (see following section for more information on the development of the term) (20-22). 'Ulysses contracts' contain the patient's refusals of treatment and do not direct or authorise specific procedures for care (22). To express their opposition to Ulysses contracts and psychiatric wills, Rogers and Centifanti (1991) came up with the term 'Mill's will' which should include both the acceptance and refusal of particular forms of treatment (23). The authors state that "unlike a consumer giving a blanket yes or no in the Ulysses and psychiatric wills, respectively, the consumer setting up a



Mill's will would be exercising the right to plan in an intelligent, self-actualising manner and demonstrating his or her awareness of how the courts have recently been approaching the substituted judgement issues in both the right-to-refuse and right-to-die cases." (23) (p. 11)

Other definitions refer to substantive versus procedural directives or advance instruction directives versus Health Care Proxies or durable powers of attorney (24;25). Substantive or advance instruction directives are similar to Mill's wills and contain instructions detailed by the patient in advance that tell treatment providers what to do or not to do in a mental health crisis should the patient become incompetent and unable to communicate his or her wishes. Procedural or Health Care Proxies or durable powers of attorney allow the individual to designate someone else to make decisions on his or her behalf should he or she become incompetent. In the USA, these two types of documents (substantive and procedural) often appear together to produce a *mixed directive* which is considered a more powerful tool than either the substantive or proxy directive (24;25).

More recently, Williams and Rigby have made a further distinction between advance statements and advance directives (26).

According to them, advance statements are:

- Usually positively framed treatment choices or requests,
- Not legally binding, but should be honoured where possible,
- Can be vague and open to interpretation.

While advance directives are:

- One of many types of advance statement,
- Treatment refusals, therefore more specific,
- Legally binding if capacity and applicability criteria fulfilled.

The report of the expert committee on the review of the Mental Health Act 1983 and the new Mental Capacity Act (2005) use the terms advance decisions to refer to legally binding documents which contain refusals of treatment and advance statements to refer to documents that include a patient's wishes and feelings which are not legally binding but should be taken into account in future care decisions

(27;28). Although advance decisions will not be valid for psychiatric treatment, advance statements are highly recommended for psychiatric treatment in both Acts.

The National Institute for Clinical Excellence (NICE) guidelines for schizophrenia and depression uses the term advance directives. NICE is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health ([www.nice.org.uk](http://www.nice.org.uk)). The following tables outline the institute’s approach:

<p><b>1.1.8 Advance directives</b></p> <p>1.1.8.1 Although there are limitations with advance directives regarding the choice of treatment for individuals with schizophrenia, it is recommended that they are developed and documented in individuals’ care programmes whenever possible.</p> <p>1.1.8.2 When advance directives have been agreed, copies should be placed in primary-care and secondary-care case notes/care plans, and copies given to the service user and his or her care coordinator. If appropriate, and subject to agreement with the service user, a copy should be given to his or her carer.</p>
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**Table 1: NICE guidelines for schizophrenia:**

<http://www.nice.org.uk/pdf/CG>

<p><b>1.1.1 Advance directives</b></p> <p>1.1.1.1 Although there are limitations with advance directives about the choice of treatment for people who are depressed, it is recommended that they are developed and documented in care plans, especially for people who have recurrent severe or psychotic depression, and for those who have been treated under the Mental Health Act.</p>
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**Table 2: NICE guidelines for depression:**

<http://www.nice.org.uk/pdf/word/CG023NICEguideline.doc>

MIND a leading UK mental health charity uses the term “advance statement (personal crisis plan for mental healthcare advance decision making)” to describe patients’ preference for care ([www.mind.org.uk](http://www.mind.org.uk)).

The report of the expert committee on the review of the Mental Health Act 1983 and the Mental Health Foundation another leading mental health charity, introduce the term “advance agreement (a plan for future crisis, developed in agreement

between service user and service provider)” in addition to the terms advance statements and advance directives (28;29).

Taking into consideration that such instruments are as unique as the individuals who design them and the highly subjective nature of interpreting their contents, it’s very difficult to make distinctions between advance statements and advance directives as they are defined by Williams and Rigby and in the draft Code of Practice of the Mental Capacity Act (30). As the preference for care study showed, patients tend to use both positively framed treatment choices and refusals in the same document (31;32).

In the literature, authors with an interest in psychiatric advance statements use the above mentioned terms rather arbitrarily to describe statements of preferences for future mental health care. For example, a lot of authors use the term Ulysses contracts and psychiatric wills for documents that contain both refusals and preferences for care and more recently Ulysses contracts are associated with irrevocability (24;33). To avoid confusion I will use the term psychiatric advance statements throughout the text (except when I quote studies that use any of the above terms) to describe patients’ preferences for care in mental health contexts and medical advance statements to describe patients’ preferences for care in medical contexts.

## **Historical overview of the development of advance statements**

### ***From Homer to 21st century***

The first oral advance statement was created by Ulysses, Homer's hero, who had braved a 10-year voyage home with his men following the Trojan War. Their journey involved a passage near the Sirens, notorious for their enchanted singing, who had tempted many an unsuspecting sailor close, only to be shipwrecked upon the rocks on which they sang. Ulysses, longing to hear their song, instructed his crew to stop up their ears with wax and to tie him firmly to the mast of his ship. Thus deafened, the crew would not give in to the enchantments of the Sirens or to Ulysses's request to sail toward them as he fell under their charms. Similarly, a Ulysses statement would allow the physician to give priority to the patient's prior competent instructions when these are at odds with the wishes expressed in a subsequent incompetent state (34).

The first written living will was described in 1969. Luis Kutner used the term to describe a document in which a competent adult could direct health care providers about medical treatments in the event of his or her subsequent incompetence. In 1975, the New Jersey Supreme Court case of Karen Quinlan focused public attention on the living will and led to the nation's first living will statute: the California Natural Death Act in 1976. Karen Quinlan was 21 years old when a mix of alcohol and drugs caused brain damage, leaving her in a permanently unconscious state. Her biological functions were maintained by a respirator and artificial nutrition and hydration. Her father sought judicial appointment to be Karen's legal guardian with authority to remove the respirator. Opposition to the father's petition was grounded primarily on claims that detachment of the respirator would constitute murder and that courts should not interfere with her physician's professional judgement in favour of continued life support. The New Jersey Supreme Court unanimously upheld the father's petition. The court posited that Karen, if competent, would be constitutionally entitled to resist life-sustaining medical intervention (35;36).

The first cases of oral advance statements that appeared in court were those of Brother Fox and Mary O'Connor in the 1980s. In *Re Eichner*, Brother Fox, a member of a Catholic religious order, had discussed Karen Quinlan's case with other members of the order and he indicated that if he was permanently unconscious, he would not like his life to be sustained. During a surgical procedure, some years later, he suffered a cardiac arrest and remained in a persistent vegetative state. Father Eichner, acting on behalf of Brother Fox, filed a petition to remove all life support. The court examined the seriousness of Brother Fox's statements and concluded that they "constituted solemn pronouncements, and therefore met the clear and convincing evidence standard applied in such cases." (37) (p. 68) The patient Mary O'Connor, was demented as a result of several strokes and while in hospital she required the insertion of a feeding tube for adequate nutrition and hydration. Her daughters refused to consent and the hospital petitioned the court for authorising the placement of the tube. Although the initial court denied the petition, the hospital appealed and the case was considered by the same court that decided Brother Fox's case. The majority decided that Mrs O'Connor's statements were not 'solemn pronouncements' but "immediate reactions to the unsettling experience of seeing or hearing about another's unnecessarily prolonged death."(37) (p. 69) In the literature, these two cases are presented as an example of the gender bias that underlined the court proceedings in honouring male versus female oral advance statements at that time. For example, Mary O'Connor's oral statement was characterised as an 'emotional response' rather than 'solemn pronouncement made after reflection' and dismissed while the one made by Brother Fox was honoured because of its cognitive superiority (37).

Following the above legal cases and changes in law to accommodate individuals' wishes regarding their health care, mental health professionals (17;20;38), user groups and lawyers started to look at the possibilities of extending living will documents and statutes to mental health care. As a consequence, the terms 'psychiatric wills' and 'Ulysses Contracts' started to appear during the eighties and legislation to cover them appeared in the early nineties in the USA (see the following section for a more detailed analysis).

The Nancy Cruzan case, again in the USA, endorsed the durable power of attorney for health care in 1990. Nancy Cruzan entered a persistent vegetative state (PVS) at the age of 24 after a car accident. Her family and friends provided “clear and convincing evidence” that Nancy would not have wanted to be kept alive in a persistent vegetative state by medical technology. The legal standard of *substituted judgement* was used to designate a surrogate health care decision-maker (that is, a durable power of attorney for health care). The durable power of attorney document authorises the decision-maker to permit withdrawal of artificial nutrition or other treatments in the event of a medically pointless situation or permanently unconscious state (36;39).

Following these and a number of other cases, two major events happened in America in 1990:

- The Supreme Court recognised that a person has a constitutional liberty interest in refusing life-sustaining medical treatment, including artificial nutrition and hydration.
- The Patient Self-Determination Act, which states that all patients upon admission to a facility or on engagement with services covered by the Act, should be provided with information about medical advance directives in their jurisdiction.

Compliance with this federal law is a requirement for Medicare and Medicaid reimbursement. Additional provisions address documentation of pre-existing advance statements, staff education and legal immunity for physicians who honour advance statements (37).

Although congress passed the Patient Self-Determination Act to promote completion of advance statements, the statute did not create any new substantive rights. As Gallagher states, “because the Patient Self-Determination Act does not purport to create substantive standards for the recognition of advance directives, and because it omits to provide any meaningful mechanism for enforcement, the significance of the Act is largely precatory.” (33) (p. 769)

All fifty states now recognise advance statement documents, and each state's version is widely available to the public through health care providers, public libraries and the state bar association (36). Psychiatric advance statements are also recognised under the generic advance directive law unless a state clearly excludes some kinds of mental health care from the generic law or has established a specific psychiatric advance statement law (see the following section for more detail) (40).

So far I have looked at the development of medical advance statements that gave rise to psychiatric advance statements. I will now turn to the legal and philosophical aspects underlying psychiatric advance statements in the USA and Europe.

### ***Legal status of Psychiatric Advance Statements in the USA***

The constitution in the USA recognises the competent individual's right to accept or refuse medical treatment (even life-sustaining) as superior to the state's *parens patriae* (the need to care for people who are not able to care for themselves due to illness) interest in prolonging life. One would expect this right to be even stronger than the state's *parens patriae* interest in providing treatment to a patient whose life is not at risk as in the cases of mentally ill individuals. Legal analysis of statutes (constitutional, common law and statutory) in the USA (33;40) suggests that in theory both those suffering from medical conditions and those suffering from mental illness may "exercise this liberty interest when they are competent, even though they may be incompetent when their choice is given effect." (24) (p. 28) In his analysis of State Statutes, Fleischner (1998) has found that "the majority of state advance directive statutes expressly or by implication apply to mental health care. Some states, however, have also enacted advance directive statutes that apply specifically and solely to mental health treatment or to some kinds of mental health treatment." (40) (p. 791)

Legal analysts also suggest that several states prevent the mental health provider and/or proxy from authorising certain intrusive forms of treatment such as ECT and psychosurgery even when the patient is involuntarily committed and a clinical finding of incompetence is established (24;33;40).

In terms of revocation, psychiatric advance statements are irrevocable after loss of competence in all except two states that have adopted the instruments. Maine and Illinois, that have both a generic and a mental health directive law, offer the individual a choice in terms of revocability (40). Individuals, who due to previous mental health illness want their psychiatric advance statements to be irrevocable, may feel that writing a document that is revocable while they are incompetent is a useless exercise. While others who either have no previous experience with mental illness or have experience with mental illness but feel that anticipation of all future contingencies is impossible, may not want to be bound by their previously expressed preferences in circumstances of an uncertain future. It seems that the



example of Maine and Illinois may provide the solution for the long run debate about irrevocable psychiatric advance statements (40).

However, the major concern of legal analysts in the USA, is not about the validity of psychiatric advance statements but the challenges of their enforceability under involuntary commitment laws and especially the distinction between instruments electing and refusing treatment (24;33). As Gallagher points out “whereas in the general medical sector extraordinarily compelling state interests (e.g. the interests of dependent children) have been required to override a person’s right to forego even lifesaving interventions, in the involuntary psychiatric arena, sufficiently ‘compelling’ interests include not only the prevention of physical harm to the patient and others but the prevention of ‘substantial deterioration’ in the patient’s psychiatric condition and the avoidance of prolonged hospitalisation.” (33) (p. 774) Winick (1996) suggests that this dilemma could be answered by applying the same principles one applies to medical advance statements. When a patient is detained under the state’s *parens patriae* power (the need to care for people who are not able to care for themselves due to mental health illness) and has executed a valid psychiatric advance statement (e.g. the document was executed and witnessed when the patient was competent) which provides a reasonable and effective alternative to the mental health provider’s intervention, his/her psychiatric advance statement should be respected (24;33). If the psychiatric advance statement includes treatments that are ineffective, unlawful or unapproved, then the state immunises mental health providers for not following the directive as in the cases of medical advance statements. In cases of involuntarily detained patients due to the risk of harm to themselves or others, with psychiatric advance statements that refuse detention and/or treatment, the state should overwrite the instruments as it would do in cases of people suffering from infectious diseases who refuse treatment or quarantine (24). “Committable but untreatable patients” that could clog up the hospitals when courts established the right to refuse psychiatric treatment as in the case of *Hargrave v. Vermont* that was mentioned in the introduction, has not happened yet in the USA because courts usually override more than 90% of such cases (5;41). To honour patients’ autonomy and self-determination in “committable but untreatable cases”, the courts usually allow the terms of the patients’ advance statement to be

implemented for 45 days before non-consensual medication is administered (5). However, when involuntarily detained patients who are in danger to themselves or others have executed psychiatric advance statements that provide rational and effective treatment alternatives, these documents should be used in order to inform mental health providers, reduce coercion and preserve the patient's autonomy and self-determination. Winick (1996) and Gallagher (1998) doubt that the courts would object to implementation of such documents under the Mental Health Acts (24;33). Moreover, Swanson et al (2000) suggest that psychiatric advance statements could be an ideal solution for those patients on outpatient commitment because an outpatient commitment order could cover transport to a facility while a psychiatric advance statement could cover prior consent for admission and treatment (42).

Furthermore, enforceability of psychiatric advance statements may be hindered by the appointment of a health care proxy. In the absence of an instruction directive, a conflict of interest (e.g. a relative who wants the patient to be involuntarily committed due to the burden of care) and other abuses (e.g. mental health professionals may coerce patients to sign such documents) may expose the psychiatric patient to unwanted treatment. Legal analysts suggest that states have to police the process of proxy psychiatric statements more intensely and create sanctions when the safeguards they have in place are not followed (24;33). For example, proxy decision makers should not be allowed to elect certain forms of experimental and intrusive treatments (e.g. psychosurgery, ECT) and they should not be allowed to act as substitute decision makers when there is a conflict of interest. Psychiatric patients should provide some general standards to guide the proxy's decision-making.

In legal circles in the USA, a psychiatric advance statement can assist treatment and limit court intervention even over the patient's incapacitated objection. A psychiatric advance statement takes effect when the patient loses capacity to make treatment decisions. If the patient objects to a determination of incapacity made by a medical team or to a health care decision made by a health care proxy, a legal determination of incapacity is required. This is an exception to the general rule that a medical determination of incapacity is sufficient to trigger the proxy's

power under the directive, making resort to the courts unnecessary when an advance statement is unchallenged (43). A more detailed analysis of the concept of capacity and its role in execution and revocation of psychiatric advance statements will follow in chapter two. Here I will provide an example of the usefulness of psychiatric advance statements in legal terms. The psychiatric advance statement retains an inherent legitimacy as the best expression of the patient's wishes. Even if a hearing is necessary to determine the capacity of the patient to revoke the advance statement, its function can be limited to the question of the patient's competency. As a consequence, the broader hearing commonly required when a patient refuses detention and treatment for mental illness will be unnecessary. McArdle (2001) illustrates this point with the following case (43).

*"The New York patient, diagnosed with a severe mental illness, had completed a health care proxy several years earlier. The proxy was modelled on the form contained in the statute and issued by the state department of health. It had been properly executed and witnessed as required by New York law. The patient had not been adjudged incompetent or had a committee or guardian appointed before signing the proxy; accordingly, a presumption of competence arose from its signing. The patient appointed a friend as her agent, but as is typical, she provided no instructions in the proxy about specific types of medical decisions. As in other states, unless the agent knew the patient's actual or likely wishes about medical treatment, she was required under New York law to make treatment decisions based on the patient's actual or likely wishes about the administration of antipsychotic medication. The patient's psychiatrist determined that the patient was no longer competent, thereby triggering the agent's ability to make medical decisions under the proxy. The psychiatrist recommended treatment with antipsychotic medication. The patient refused to consent to the treatment. The medical staff informed the agent, who, based on the recommendation of the patient's psychiatrist, provided a written consent to the administration of antipsychotic medication. The consent form contained a full recitation of the patient's medical diagnosis and prognosis, described the treatment determined to be medically necessary, and informed the agent of the risks and benefits of the treatment. The patient's court-appointed attorney did not object to treatment with antipsychotic medications. The facility sought a court order because of the lack of precedent on the use of a health care proxy to administer antipsychotic medication when the patient refused to consent to treatment. The court, based on the agent's consent to the treatment, ordered treatment and waived the hearing ordinarily required in New York before treating a patient for mental illness over objection." (pp 154-155)*

In summary, the legal validity of psychiatric advance statements in the USA is unquestionable. Legal analysts believe that psychiatric advance statements not only could bridge the gap between the rights of health and mental health patients but also could reduce court involvement. However, great attention is still needed in terms of judicial, police and other official resources for the implementation of such instruments.

### ***Legal status of Medical and Psychiatric Advance Statements in Europe***

In the European Union there is no clear legislation as yet, about medical and psychiatric advance statements.

The World Health Organisation for Europe authorized in March 1994 an article called "Principles of the Rights of Patients in Europe." According to this article, when a patient is unable to express his or her will and medical intervention is urgently needed, the consent of the patient may be presumed unless there is evidence from his/her previous declaration that consent would be refused in the situation (44).

The Convention on Human Rights and Biomedicine of the Council of Europe contains an article on "previously expressed wishes." According to article 9 the "previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account." (44) (p.186)

A characteristic of the above-mentioned legislation and declarations is their vagueness surrounding the functions and implementation of advance statements. These laws limit themselves to the recognition of the validity of an advance refusal but practical problems are in general neither explained nor regulated. This is in a certain sense paradoxical because under existing law it is not so much the principle of an advance refusal that is disputed but its implementation. This paradox is observed in the legislation and declaration of individual European countries within the European Union such as Finland, with the exception of Danish law. Danish law about an advance refusal is not integrated in the patients' rights legislation and contains some rules about its implementation. For example, on 14 May 1992, an amendment of the medical law incorporated a new section 6a that states: "Any person who has attained the age of majority shall have the right to draw up a living will. The will shall express the testator's wishes concerning the treatment to be administered in the event of his being in a situation where it is no longer possible to exercise the right of self-determination in any other way."(44) (p. 186).

According to Nys (1997), European law should clarify many aspects of advance statements, some of which are outlined below (44):

- Who will decide and according to what criteria the (in)competence of the patient?
- From what age can an advance statement be made?
- Is an advance statement limited to refusal of life-sustaining treatment (Denmark) or has it a larger scope (Finland)?
- Is it limited to terminal conditions; can “basic care” be refused?
- Are there any formalities to be respected; how can an advance statement be revoked?
- How can one ensure that physicians are informed about the existence of an advance statement?

## *Legal status of Medical and Psychiatric Advance Statements in Britain*

### **Medical advance statements**

Medical advance statements have legal effect in England in common law, providing they meet the following criteria for validity:

1. the patient is competent (be competent) at the time the decision is made,
2. anticipatory consent is based upon adequate information,
3. the patient is free from undue influence or coercion (in other words, gives voluntary consent),
4. the patient intends his refusal to apply to the circumstances which subsequently arise (3).

As far as the enduring power of attorney is concerned, under the 1985 Act for Property and Affairs, the granting of a power of attorney may survive after the onset of the creator's incompetence. However, the Act does not cover decisions about medical treatment since it is restricted to the "property and affairs" of an individual (3).

Comprehensive statutory legislation covering medical and psychiatric advance statements has been approved in 2005 (27). The new Mental Capacity Act and the report of the expert committee on the review of the Mental Health Act 1983 both tackle the issue of advance agreements about care and advance decisions to refuse treatment in general health and mental health contexts (27;28). As it is the case in common law, a patient has the right to refuse medical treatment but does not have the right to suggest his/her preference for particular treatments. Both Acts establish the right of a proxy decision maker (Lasting Power of Attorney) to make mental health and medical treatment decisions on behalf of the incompetent patient. More specifically, the Mental Capacity Act 2005 establishes the right of a competent person of 18 years or over to state orally or in writing his/her wishes to refuse specified medical treatment (even life-sustaining treatment) at a point in the future when that person is no longer competent to make treatment decisions. The new Act makes a distinction between "the legal status of a general advance statement reflecting an individual's wishes and feelings about how s/he wishes to be treated and a valid and applicable **advance decision** to refuse a specified medical procedure or

treatment. Both general advance statements and advance decisions are a means whereby patients, through advance planning, can continue to influence the treatment they receive in the event that they lack capacity to express their views in the future. A general advance statement about wishes and feelings operates in a different way by influencing the way doctors determine best interests. A general advance statement is an expression of past wishes and feelings and so forms part of the best interests checklist.”(30) (p.84)

The draft Code of Practice doesn't provide a prescribed form for writing advance decisions but suggests that such forms should include as many details as possible about the identification of the person who executed the document and should be signed by independent witnesses. An advance decision is valid when specifies the treatment refused, is applicable to the actual situation and has been reviewed and is updated regularly. The draft Code of Practice specifies three events that invalidate an advance decision:

- That the person has withdrawn the decision while s/he still had capacity to do so;
- That after making the advance decision, the person has created a Lasting Power of Attorney (LPA) giving power to a donee to give or refuse consent to the treatment specified in the advance decision (an LPA conferring different powers would not affect the advance decision); or
- That the person has done something which is clearly inconsistent with the advance decision which implies that s/he has had a change of mind.

A competent adult has the right to withdraw and change advance decisions at any stage. The new laws immunise health care professionals when they follow valid oral and written advance decisions but could also subject them to a claim for damages for battery or to criminal liability for assault if they don't honour such valid documents. Health care professionals who have conscientious objections should transfer care of the patient to another health care professional (30).

The Mental Capacity Act 2005 has been welcomed by most professional bodies and advocacy groups in this country (45). However, certain criticisms have been voiced on a number of issues and in particular to the provisions on advance decisions (45). The Making Decisions Alliance, which comprises of a wide range of organisations

and groups working with people who have difficulty in making or communicating decisions, expressed their dissatisfaction in the exclusion of advance preferences for care from the bill. They strongly suggested that advance preferences for care should have the same legal status as advanced refusals of treatment (45). The Royal College of Physicians expressed their opposition to the tight criteria of validity of advance decisions because of the difficulty inherent in accurately predicting the exact circumstances one would be for their advance decision to apply. They fear that they would still have to interpret patients' oral and written advance decisions with the advice of the patient's relatives which may make them vulnerable to liability. Another of their concerns was about increase of their workload and the lack of guidance regarding the best means of registration and availability of such documents especially when they would be most needed (e.g. emergency situations) (45). The Mental Capacity Act 2005 puts the responsibility for drafting advance decisions to the individual which may leave general practitioners to cope with the extra time and resources for helping individuals who would want their GP to be responsible for registering and disseminating such documents (27).

### **Psychiatric advance statements**

Regarding the validity and implementation of psychiatric advance statements, the Mental Capacity Act 2005 and the revised draft Mental Health Act 1983, paint a rather confusing and disappointing picture (27;28). On the one hand the Expert Committee's Report on the review of the Mental Health Act 1983 suggests that advance statements about care and treatment for mental disorder will not have statutory validity and on the other hand it suggests that patients and mental health professionals should routinely create psychiatric advance statements (see Table 3).

12.12 In our Draft Proposals we canvassed the possibility of recommending that, in reflection of the principle of patient autonomy, advance statements be given statutory recognition in any future mental health legislation. We suggested that advance statements be recognised as expressions of a patient's capable wishes, and that they be allowed to prevail in the same circumstances under the new act as those in which the wishes of the patient with capacity at the time would be allowed to prevail. Although the proposals attracted considerable support, we now acknowledge that it would be difficult to accord statutory recognition only to directives about care and treatment for mental disorder.

12.13. However, we recognise that certain forms of advance healthcare statement already have full effect in common law, although they have yet to be recognised



<p>by act of Parliament. We therefore recommend that the necessary provisions be introduced in statute and complemented by the Code of Practice, to ensure both that the creation of an ‘advance agreement about care’ is routinely considered by care teams and patients and that when created these agreements would have sufficient formality to be regarded as proper statements of a patient’s capable wishes. In essence an advance agreement about care would represent the written outcome of a discussion between a patient, with the necessary capacity, and his or her care team. It would address the patient’s treatment preference (if any) in relation to any possible future care and treatment for mental disorder, and it would have to be taken into account as a capable expression of the patient’s preferences should treatment become necessary at a future point when the patient has lost capacity.</p>
<p>12.14. We are firmly of the view that the creation and recognition of such agreements would greatly assist in the promotion of informal and certainly consensual care. Patients and care teams would become used to negotiating an agreed package of care to be implemented in the case of relapse.</p>
<p>12.15. Accordingly, we recommend that an obligation be placed on the care team to provide all patients, prior to discharge from compulsion, with information about and assistance with the creation of an advance agreement about care. We further recommend that any discussion concerning an advance agreement should involve the patient’s nominated person and/or advocate and, with the patient’s consent, any relevant carer. The details of the form to be taken by advance agreements and the matters they might include should be contained in the Code of Practice, which should set out guidance as to how advance agreements can be constructed in such a way as to achieve recognition in law.</p>

**Table 3: Expert Committee’s Report on the review of the Mental Health Act 1983 (pp 106-107)**

The Mental Capacity Act 2005 and its Code of Practice reinforces the disparity between medical and psychiatric advance statements by allowing detained psychiatric patients to refuse medical treatment but not psychiatric one (see Table 4) (27;30).

8.31 Where a patient is liable to be detained under the Mental Health Act 1983, the contents of any advance decision to refuse treatment for mental disorder may be overridden by the compulsory treatment provisions of section 63 of that Act which provides that “the consent of a patient shall not be required for any medical treatment given to him for the mental disorder from which he is suffering” [and is not treatment that falls under section 57 or 58 of the 1983 Act]. Treatment for mental disorder may therefore be given under the 1983 Act without the patient’s consent and even where the patient is making or has made a decision to refuse a particular treatment for that particular condition. However, an advance decision to refuse treatment for a physical condition, as opposed to a mental disorder that falls within the application of section 63 of the 1983 Act, could still be valid and effective regardless of whether the patient was liable to be detained or compulsorily treated under mental health legislation.

**Table 4: Extract from the draft Code of Practice for the Mental Capacity Bill (p. 91)**

With the new Mental Capacity Act 2005 and the draft revisions of the Mental Health Act 1983, a great opportunity to give statutory recognition to psychiatric advance statements is lost as well as is the opportunity to bridge the gap between mental health patients’ rights and the rights of patient’s in general medical settings. Furthermore, in what way could one differentiate between psychiatric advance statements as they are defined by the above Acts and the Care Programme Approach Plans?

### **Care Programme Approach**

In 1991 the Care Programme Approach and the Health of the Nation policies came into effect (The Department of Health) in order to maximise user and carer involvement. The Care Programme Approach (CPA) is the "cornerstone" of current policy for mental health services. It arose out of concern about inadequate follow-up care for people leaving psychiatric hospitals, as evidenced in a number of well-publicised scandals. The Care Programme Approach emphasises various elements of good practice including: the assessment of the user's health and social care needs by a multidisciplinary team; an agreed plan of care and treatment; the allocation of a "key worker" with responsibility for maintaining contact and monitoring the implementation of the plan; and regular reviews (7).

Users and their carers should be involved in discussions about their proposed care programmes (CPs) so that they can discuss different treatment possibilities and agree the programme. Carers' involvement is crucial because they often know a great deal about the user's life, interests and abilities as well as having personal experience of the user's mental health problems.

Research on the effectiveness of the CPA has yielded mixed results. Tyrer et al (1995) suggested that the supervision register (a form of *at risk* register- aimed to ensure that someone at risk was actively followed-up, and to reduce the chances that he or she will slip through the community care net) led to greater success in maintaining contact with vulnerable patients, but was likely to lead to more psychiatric admissions (46). Phillips (1998) suggested that when there were serious disagreements between the users of mental health services and professional carers (e.g. their psychiatrist) over the nature of their problems or aspects of their treatment, the users felt that their viewpoint was not being heard and that they had to struggle to get changes in treatment (47). Lawson et al (1999) suggested that user involvement in needs assessment and decision-making in a survey of fifty CPA meetings was poor, as was knowledge of care planning and information provision to users (48). Furthermore, Allen (1998) in her study of experiences and views of carers reported that carers felt excluded and ignored by mental health professionals (49). This suggests that the Care Programme Approach system may be meeting the needs of professionals by ensuring regular client review and clear documentation of the care plan but that patients and carers can feel subject to a degree of coercion in Care Programme Approach meetings.

Psychiatric advance statements are designed to promote patients' empowerment, autonomy and self-determination. Therefore, the opportunity to complete psychiatric advance statements outside the Care Programme Approach meetings would closely involve patients in their care and consequently improve their autonomy. In addition, independent researchers and patient representatives who could help patients to complete psychiatric advance statements outside Care Approach Meetings, would be more likely to advocate patients' rights and preferences. Furthermore, this arrangement would not burden clinicians whose time and expertise were limited in terms of advance care planning.

### **The validity of the preference for care study and qualification of the preference for care booklet as 'advance statement about care'**

According to the new Mental Capacity Act 2005, the preference for care booklets qualify as advance statements about care because they contain information for preferred psychiatric treatments, treatment refusals and proxy decision makers. Conducting the preference for care study on patients who were about to be discharged from section falls within the recommendations of both the report of the expert committee on the review of the Mental Health Act 1983 and the Mental Capacity Act 2005 (27;28).

Due to medico-legal implications associated with psychiatric advance statements at that time, an academic lawyer (John Dawson) was consulted prior to the design of the preference for care booklet. The legal issues considered in planning this study and designing the booklet were (50):

- The criteria and process for assessing the competence of patients to complete the booklet.
- Whether completion of the booklet by a competent patient might later preclude provision of treatment a clinician believed was indicated.
- Whether clinicians might be exposed to any additional forms of liability if treatment did proceed contrary to patients' stated preferences.
- Whether completion of the booklet might mean that clinicians invoked the authority of the Mental Health Act even more frequently in order to override patients' preferences.

Many statements in the preference for care booklets completed as part of this research would meet the validity requirements that are outlined at the beginning of this section and might therefore bind clinicians in certain respects concerning later treatment options (see booklet in the pocket attached at the back of the thesis). There were even aspects of the methods which enhanced the validity of the booklet as an advance statement.

The inclusion criteria for the study required that only competent patients would be approached for consent. However, to be absolutely certain that the patients we approached were able to understand the process of the trial and the meaning of their advance statements, we asked them to re-state in their own words their understanding of both the aim of the study and the purpose for drafting their advance statements. Therefore, the competence of the patient was to be specifically assessed at the time their statement of preferences was made; those statements would often relate to particular forms of treatment (even named medications) of which these patients would have had considerable experience; the patients' preferences would be clearly evidenced in writing; and the booklet's completion would be supervised by experienced health professionals (myself and another researcher) who could verify the circumstances. These features of the research context would buttress the case that the patient's statements in the booklet would meet the law's criteria for an effective psychiatric advance statement that should ordinarily be honoured.

One question in the booklet was particularly significant in this regard. It asked patients to specify treatments they would not want to receive. Typical responses to this question ('No Haloperidol', 'No injections') could be viewed as specific prohibitions of treatments that would intrude upon the patient's person. For a clinician then to provide that treatment, despite that prohibition, might constitute a battery of the patient, unless this was authorised by mental health legislation or justified under common law principles of necessity (51).

### **The limitations of psychiatric advance statements in the preference for care study**

There are nevertheless distinct limits to the effectiveness of advance statements concerning mental health care. An advance statement cannot require treatment to be provided that is unlawful or unethical or which is not clinically indicated or for which the resources are not available: i.e., it does not create any duty to provide inappropriate or additional care. And the patient's stated preferences can still be overridden if the clinician can rely on some form of legal authority or justification for providing treatment without consent. Sectioning the patient under the Mental Health Act 1983 will usually provide that authority, in the case of treatments 'for mental

disorder’; and ignoring the patient’s instructions would also be justified to prevent suicide or other serious physical harms, provided the patient is sectioned as soon as practical if compulsion continues (50).

### **Elevating use of the Mental Health Act due to the preference for care study**

In relation to this research, the rule that the authority to treat provided by the Mental Health Act may override an advance statement raised the prospect that patients who completed the booklet might be more exposed than the control group to compulsory treatment under the Act. That is, faced with clear evidence in the booklet of the patient’s negative preferences for care (‘No injections’), clinicians who felt the need to override such preferences might perhaps invoke the compulsory treatment process more often than they otherwise would.

It was decided that even if this was the case this research would not be unlawful for this reason. It is not unlawful to listen carefully to patients’ preferences or to record them. Nor need there be any illegality in the subsequent sectioning of a patient to obtain the authority to override their preferences. Provided the patient meets the relevant legal criteria, that is a proper use of the Mental Health Act, and one which is arguably in such patients’ interests, because it ensures they receive the benefits - of the procedures, documentation and review entitlements – that the Act deliberately provides for those treated under compulsion. Completion of the booklet simply provides one additional means through which patients’ preferences might be known.

### **The disclaimer at the end of the booklet**

One change made in the methods was to add at the end of the booklet a disclaimer, the aim of which, was to reduce the chance of a patient considering they had been misled or misinformed as to the binding character of their statement of preferences. The disclaimer was to alert the patient to the fact that they might still competently alter their own preferences at a later time; and to make it clear that in some situations their preferences might be lawfully overridden. This disclaimer had to be carefully worded. We did not wish to indicate the booklet was meaningless (its contents would still provide good evidence of the patient’s views); but nor did we wish patients to overestimate its legal effects.

In summary, medical advance statements which have been valid under common law have been given statutory validity in the UK under the new Mental Capacity Act 2005. However, psychiatric advance statements will continue being valid under common law but will not be given statutory validity. This may not only undermine the value of such documents but could put off patients from completing such documents altogether. In contrast to USA where psychiatric advance statements are seen as means of bridging the gap between medical patients and psychiatric patients, in the UK this gap still remains wide open.

So far I have looked at the changes in psychiatric services, the development of the consumer advocacy movement and the passage from Ulysses initial advance statement to modern medical and psychiatric advance statements. The legal aspects underlying the design, implementation and revocation of such documents has been discussed in different geographical contexts such as the USA, European Union and the United Kingdom. In the following section I will turn to the philosophical issues underlying medical and psychiatric advance statements.

## **Philosophical issues underlying medical and psychiatric advance statements**

### ***Medical advance statements***

The cases in court (e.g. the Nancy Cruzan case) brought forward a variety of moral and ethical debates concerning the use of medical advance statements. For example, one argument would run as follows: young and healthy individuals should not be allowed to create directives refusing treatment in the event of serious and permanent injury because of their lack of experience in such adverse circumstances and because their values might change if a disastrous illness or injury comes years later. Another point made was that no competent person may ever prospectively decline treatment for a future period of incompetence because the person will have no first-hand experience of what life is like as an incompetent individual (37). However, the same argument could apply to marriage or choice of profession, decisions we make when we are young. How do people know that they want to spend the rest of their lives with the same partner or in the same job?

Two particular views are associated with advance statements at present:

- The conservative view that rejects the terminal label until death is about to happen (a matter of hours), therefore cancelling out much of the impact of the advance statement.
- A liberal view that takes the position that any irreversible condition that ultimately will result in the patient's death should be considered a terminal condition, including a persistent vegetative state. Proponents of this view accept advance statements as the cornerstone of promoting self-determination and autonomy.

In the following section the debate surrounding the liberal view will be explored.

### **Liberalism**

Medical ethics in the USA and the post-industrialised countries of Europe are powerfully influenced by liberalism. Liberalism is a political point of view that people should be left as far as possible to decide their own course of life and



follow their own values as long as they do not harm others. But how is this theory translated in the practice of medical decision making? How do medical professionals decide what is right or wrong in a case like Miss B? Western medicine uses the analysis and balancing of four main principles:

- Autonomy: the right to make decisions about one's own life and body without coercion by others.
- Beneficence: doing good to others.
- Nonmaleficence: not harming others.
- Justice: a people should be treated equally (39).

However, there are limits to the extent to which an advance statement can or should promote individual autonomy (39).

Some have objected to the priority advance statements may give to the wishes of the individual, abstracted from the context of their social group (52). Proponents of this view believe that the individualism inherent in liberalism induces selfishness because it would reject the individual's obligations to family, state, ethnicity, etc. However, the majority of people do commit themselves to such obligations and can, in any case, make rational medical decisions apart from their 'significant others'. However, in reality our individual decisions and wishes are shaped through the process of identification with significant others within a specific social and historic context. An individual who is still able to reflect on the process of their views' formation is not only a wise person but also an autonomous one. His or her advance statements will probably express their character within the social and cultural conditions that shaped it. As Ikonomidis and Singer (1999) state, "it is impossible to think of ourselves except as part of ongoing communities, defined by reciprocal bonds of obligation, common traditions, and institutions. Therefore, liberal conceptions of autonomy are not purely individualistic as critics say." (52) (p. 523) This objection, it seems, can be overstated.

A second objection against the use of advance statements states that giving too much priority to liberal autonomy could restrict social justice (52). A patient could express their preference for a variety of medical resources regardless of the impact

on the welfare of others. What happens if a person states their desire to receive a very scarce and expensive treatment when other people are being denied basic medical resources? Does promotion of autonomy guarantee that the patient will get whatever she/he wants? Surely not. So patient self-determination is to be understood in the context of “informed consent” or “informed refusal” rather than in the context of “consumer sovereignty.” (52) (p. 524) Within this context, social justice can be protected by taking into account the concerns for equitable resource allocation that may arise in advance care planning.

A third objection refers to justifiable paternalism. A strong liberalism would accept that the right to be self-determining is inviolate and therefore no act of paternalism is justifiable unless to protect others from harm (52). However, in most societies some paternalistic acts are accepted, such as those from parents to children, from a competent adult to another who is chronically incapacitated (e.g. someone with severe brain damage), and even when the beneficiary is competent (e.g. all drivers should wear seat belts). Critics of advance statements wonder whether they should be respected in cases when medical treatments could clearly benefit the individual who is now incompetent. To answer the dilemma one can make the distinction between two forms of paternalism: ‘hard paternalism’ and ‘soft paternalism’ (1;52). ‘Hard paternalism’ refers to the enforcement of certain values and judgements upon people for their own good (e.g. one should avoid recreational drugs, wear seat belts). ‘Soft paternalism’, on the other hand, focuses only on the right of the state to prevent self-harmful behaviour that is not voluntary (e.g. the behaviour is the result of severe brain damage). While most liberals will discard ‘hard paternalism’ as a principle, they may accept ‘soft paternalism’ in cases of incompetent individuals who are unable to give informed consent by acting on that person’s best interests. In cases of competent individuals who have become incompetent due to a disastrous illness like Miss B, advance statements might then be overridden only when there is evidence that the patient’s wishes were not voluntarily made or when there is evidence that the person was not adequately informed about their condition at the time the directive was made. I believe that if the patient has not referred to a particular treatment option in his/her advance statement (e.g. has only given a general statement such as “do not resuscitate”) when competent but there is evidence that they might benefit from

that treatment when in a state of incompetence, then by following the principles of beneficence and non-maleficence and acting according to the best interests standards, that advance statement should be overridden.

Finally, another argument against the concept of liberal autonomy underlying advance statements comes from feminist ethics (39;52). Feminist ethics may reject liberal autonomy because of its emphasis on questions of justice over questions of care. In the 1970s a group of dissatisfied female physicians in Harvard published a “how-to” book that covered a broad spectrum of health problems. They used simple language and their focus was “on values such as co-operation, nurturing and bonding.” (39) (p. 23) They argued for the importance of context-based values such as the importance of personal relationships rather than abstract notions of rights (39). In terms of advance care planning, they argued that a strong liberalism did not embrace the preservation and protection of personal relationships due to its emphasis on the wishes of the individual. This argument is overstated, in my view, because people can readily take into consideration the value of such relationships when formulating an advance statement and the research shows this is the context in which their implementation is most successful (53).

### **Autonomy and personal identity**

In addition to the above arguments, another set of objections for the validity of advance statements is directed towards the notion of personal identity inherent in the principle of autonomy. A frequently quoted hypothetical example is that of a demented patient who prior to his illness held his cognitive powers in the highest regard such that he would prefer to die rather than live without them (54). He has stated his values both orally and in writing so that the people close to him and his physician are aware of them. As his disease progresses reason leaves him, initially frustrating him but eventually leaving him in a state without recollection of his former talents and skills and as a result without grief at having lost them. In this case, the patient’s personality and values have changed irreversibly. The dilemma in this case lies in the choice between honouring his written wishes by withholding care and ending his life, on the one hand, and ignoring them and paying attention

to his current interests and desires, on the other. Which ‘person’ should we recognise as the proper subject of this decision: his former or current self?

To decide whether an advance statement must be followed or not in the case of a patient who loses his/her personality irreversibly (i.e. through dementia), bio-ethicists turn to the distinction between “critical and experiential interests” (55;56). Critical interests refer to our long-term values and beliefs, our hopes and aims that provide genuine meaning and coherence to our lives. Our adherence to these interests, explain why many of us care about how the final chapter of our life turns out. Experiential interests, on the other hand, involve the pleasure and pain we experience through different life experiences, such as hobbies, eating well, socialising or just working hard on something. In many forms of dementia a patient usually goes through three phases:

1. The patient still has critical interests.
2. The patient has experiential interests only.
3. The patient has permanently lost self-awareness and interests in any form.

The question that arises from the above analysis is: at what stage do we follow or override the advance statement given that there is an important overlap between critical and experiential interests? Should physicians respect the person’s autonomy, represented in his/her advance statement and withhold medical treatment, even though he/she still has experiential interests? Is it possible to make compatible a patient’s experiential interests with his/her critical interests which conflict with them (e.g. the demented patient is happy when he gets his food although his cognitive ability is lost)?

To solve this dilemma, bio-ethicists point to the limits of autonomy and the need for specific advance statements for different kinds of illnesses and cases. They also underline the need to inform patients about the risk of vagueness and interpretation of such documents and the necessity to state conditions in which they themselves would want their advance statements to be overridden. Assigning substitute decision makers will also help to handle limitations arising from interpretation of the patients’ preferences and fill potential gaps in documentation (55;57).

The discussion so far has been concerned with the general legal and philosophical issues presented by advance statements for health care and its refusal. The focus has been on end-of-life decisions, because that is the main focus of the existing literature in this field. Many similar general issues arise concerning advance statements in mental health care, such as the question of how specific such directives should be, and circumstances in which they should be honoured or overridden.

### ***Philosophical issues underlying psychiatric advance statements***

The main philosophical debate around the implementation of medical advance statements is focused on the *limits of autonomy* (e.g. should the value of respect for autonomy dominate the value represented in the “do no harm” principle?) inherent in cases of terminal illness. In contrast, the focus of the debate about implementation of psychiatric advance statements is on the *conflict within autonomy* (should we respect the former autonomous decision manifested in the psychiatric advance statement or the present minimally rational and autonomous dissent?) (21).

Liberals fear that psychiatric patients will be coerced into signing documents that leave decisions about whether they will be hospitalised and treated to their doctors’ discretion. Conservatives on the other hand worry that psychiatric advance statements may prevent treatment of patients who would otherwise suffer needless pain or might inflict such pain on others (38).

How can a psychiatric advance statement protect the individual’s autonomy and the public through time? I will try to illustrate the different sides of the debate by examining the following hypothetical case.

*Mr X is a 40-year-old male married with two children. He works as a business consultant for a large company and he is diagnosed with a bipolar affective disorder. His manic-depressive mood swings have reached psychotic proportions. During a period of remission he realises how destructive his psychotic episodes are to all involved and he has reviewed the likelihood of a recurrence with his psychiatrist. He has instructed her to do whatever she reasonably can to prevent another relapse, even to treat him against his will at the time should he then need but refuse medications or hospitalisation. A few months later, as he progresses from a normal, euthymic state toward a full-blown manic psychosis, he passes through a hypomanic stage, much as they had foreseen. He gradually becomes more energetic and requires less sleep. His speech grows more rapid and pressured, reflecting his increasingly racing thoughts. His mood expands and is alternately euphoric and irritable, and he becomes more and more grandiose and reckless in his actions, much to the distress of his family, friends, and co-workers. He spends large sums of money on things he does not need and would not normally purchase, seriously depleting family resources. He makes sexual advances toward female neighbours and co-workers. When family and friends attempt to intervene and to persuade him to seek psychiatric care, he resists. His mood has become still more expansive and irritable, and he denies even having the illness for which he has been regularly taking a prophylactic medication, lithium carbonate. Instead, he throws away his medication, refuses to see his psychiatrist, and dismisses the possibility of any treatment to help him through the manic episode. Nonetheless, he does not yet present, as defined by the law, a danger to himself or others, nor is he incompetent or so gravely disabled as to prevent him from being able to meet his biological needs for food, clothing, and shelter. Thus he does not meet the grounds for involuntary hospital admission.*

The above case is a hypothetical one that most psychiatrists and mental health professionals would recognise. People like Mr X in the above hypothetical example suffer from a recurrent but treatable psychotic disorder that causes a change of personality and behaviour. A person's personality is the complex pattern of values, preferences and beliefs in which the person manifests who he/she is and wants to be. We are mainly concerned with our values and our personality when we plan for our own future, our happiness and security.

The notion of personality and biographical identity is directly related to the concept of autonomy (1;21;22;56). A person's identity is formed in stories that both express and create the unity of a person's life. As stories, psychiatric advance statements presuppose the unity of the patient's life and try to contribute to that unity, not by making the different phases identical, but by trying to create a meaningful whole that covers all of them. As a consequence, if Mr X had made an advance statement when competent, he would have made it in order to plan for his future. His psychiatric advance statement would probably indicate that he wants hospitalisation under special conditions even if, once in those conditions, he would not consent to it. He would want his wishes to be self-binding because planning for the future would be for him a key element for leading life as a person. In other words, he recognises that crises are part of his life, in that they have occurred in the past and are likely to occur again in the future. His psychiatric advance statement is not simply a document containing orders to his psychiatrist but is part of the process of communication between him and his doctor about what courses of action are preferable within his life history. Mr X tries to communicate that he is a person who needs help and support to keep a hold on life, especially during a period of crisis.

### ***Disorders of mind versus changes of mind***

However, the dilemma that arises in these circumstances is which is "the most authentic manifestation" of Mr X's will?

- The acceptance of the fallibility of his rationality hence his self-binding wishes? Or

- The acceptance that changing his mind and developing new values in changed situations are also important parts of leading his life as a person?

In the case of Mr X, a change of personality is caused by a disturbance of (as yet unknown) brain function. The coherence of his personality (values and beliefs) is interrupted, and the patterns underlying his present objection to treatment are less stable and rational than those underlying his advance statement. The question that arises is: are there any criteria by which to determine when one is witnessing a patient's genuine change of mind rather than a switch of his/her personality, which was foreseen by the patient who wanted to be treated in these conditions?

To attend to this argument properly it is important to define truly rational autonomous decisions versus irrational ones. According to philosophers, the terms rational, reasonable and irrational apply both to personality characteristics and specific choices and actions (1). Reasonable is equated with sensible which is the opposite end of the unreasonable continuum, while irrational is the opposite end of the competent continuum (see Figure 1).

Reasonable \_\_\_\_\_ Unreasonable  
 Competent \_\_\_\_\_ Irrational

**Figure 1: Reasonable-Unreasonable and Competent-Irrational continuums according to Feinberg**

What differentiates the two continuums is the existence or absence of voluntariness and control. For example, mental illness impairs cognitive functions and subjects individuals to actions based on delusions and factual distortions which are not fully voluntary. Unreasonable choices on the other hand, are voluntary and can be made by fully competent persons either in-character and as part of their self-image (e.g. extreme sports) or out-of-character due to weakness of will (e.g. getting drunk) or perverse behaviour (1). While mental illness and its subsequent incompetence deprive the individual of exercising control over his/her actions, unreasonable choices and actions are still under the actor's control. Using coercive powers to restore or prevent unreasonable personality characteristics



and/or actions is seen as an infringement of a person's autonomy in most liberal western societies. The opposite is true for persons who suffer from mental illness as societies develop laws (e.g. Mental Health Act 1983, Mental Capacity Act 2005) to protect both the individual who suffers from mental illness and society. However, this clear-cut theoretical separation of irrational and unreasonable does not apply so clearly in every day life since definitions of health and mental health are socially constructed (58-61). To expand on the social construction of mental illness, psychiatric diagnosis and its consequences is beyond the scope of this thesis. For the current argument of truly autonomous decisions versus unwilling changes of mind, which is relevant to psychiatric advance statements, the position of persons who accept the mentally ill role and whose competence can be restored is explored.

If we accept that irrationality and its consequent loss of competence are the product of mental illness and that certain forms of treatment can restore competence although they can not cure mental illness, then admitting that the decisions of the "former" and "later" self of the mentally ill person can be equally voluntary is the decisive criterion for the validity of a psychiatric advance statement (1;22;62). Another approach, the "cool moment" theory, states that the moment at which the person who has conflicting preferences is neither in the grasp of the one desire, nor in the grasp of the second is the decisive criterion (22). Dworkin provides a third approach according to which the best criterion is the ability of the individual to reflect upon their critical (higher-order preferences and values: e.g. importance of one's preservation of dignity) versus their experiential (lower-order desires: e.g. experience of pleasure and pain) interests (56). According to Dworkin, the critically reflected preferences of an individual as formulated in the psychiatric advance statement are of crucial importance and must receive priority above the lower-order desires expressed in cases of a crisis (22;56). Along the same line is Dresser's concept of 'self-paternalism' that "suggests that every individual has a 'true' identity, one that is best equipped to make long-term decisions on the individual's behalf. Thus, although a person's desires will vary over time, decisions of the true identity should prevail over contrary expressions of choice. The Ulysses contract would furnish a mechanism through which the state enforced certain wishes of the true identity." (20) (p.15)

Finally, while the previous philosophical approaches focus on the superiority of cognitive functions in rational decision making, psychological approaches focus on a mixture of cognitive and emotional concepts such as insight as the most important determinant of truly autonomous decisions of mentally ill persons in relation to execution and revocation of psychiatric advance statements (61;63). A more detailed analysis of the cognitive versus emotional components of competence will follow in chapter two. Insight into one's mental illness involves the patient's recognition (cognitive and emotional) that he/she is suffering from an illness and the realisation that the illness is mental as well as the ability to re-label the experience of certain mental events (e.g. the sound of a voice is an auditory hallucination) as pathological (63).

According to the above approaches only wishes that are insightful, voluntary, "cool" or reflected should count as true expressions of the patient's values. However, in practice it is difficult for the psychiatric patient to formulate his/her wishes voluntarily in a cool moment or through critical reflection. It is also difficult for the doctor to decide whether the wishes are based upon the above criteria because the criteria themselves are part of a process of interpreting, a process that requires critical examination. The psychiatric advance statement grows out of and is itself the source for further communication or narrative work. The psychiatric patient is not a self-sufficient individual directing his/her own life but a person in distress and in need of care. From this narrative perspective, autonomy is based upon biographical work and the embeddedness in social relations. As a consequence autonomy is not equal to independence but is developed in relations of dependency. Similarly, rational decision-making is dependent on the patient's mental capacity, which as it will be discussed below is not an all or nothing thing but highly dependent on the situation. As long as the patient has enough insight into his illness and is competent to decide about his mental health treatment, his psychiatric advance statement should have equal weight as his contemporaneous decisions.

To summarise, a patient's expressed wishes during a period of crisis should not be accepted at face value but neither should they be deemed totally irrational and

irrelevant. Rather they should be interpreted in the light of the patient's life history, a history that is informed by the communication between the patient and his/her mental health carers including formerly discussed psychiatric advance statements.

## **Effectiveness of medical and psychiatric advance statements**

### ***Lessons learnt from medical advance statements***

Early studies focused on how common advance statements were in America after the passage of the Patient Self-Determination Act in 1990. Although there was an increase in the number of patients reporting discussions about end-of-life issues, there was no clear increase in the completion of legal advance statements. In the early 1990s only between 1% and 40% of hospitalised patients reported having an advance statement. The patients who completed them were mainly diagnosed with incurable cancer or AIDS. Only 5% of patients who were transferred from the emergency room to the intensive care unit had advance statements, while their availability when patients were transferred from nursing homes to hospitals was generally poor. Most physicians did not know when their patient had completed one (53).

To improve completion, interventions were tried such as provision of counselling by hospital patient representatives or educational material (64;65). Meier et al (1996) randomised 200 consecutive patients admitted to a teaching geriatric hospital in New York City into intervention and control group within 24 hours of their admission (64). Within 48 hours of their admission patients in the intervention group were approached and interviewed by one of two trained counsellors from the hospital's office of patient representatives. All intervention patients whom the attending physician judged had the capacity to make medical decisions were interviewed by the counsellors. These patients were counselled about advance statements and were given the opportunity to complete a health care proxy, if they had not already done so. For those patients who already had an advance statement, the representative reviewed the advance statement with them and reported the recommended changes. Existing and newly made advance statements were reported in the inpatient hospital chart. Patients in the control group received standard care. The main outcome measures included documentation of:

- a copy of the advance statement form
- documentation by the patient representative of the presence of a health care proxy

- any notation about an advance statement by a health care professional.

There were no significant baseline differences between the two groups. The intervention group performed better in all of the outcome measures. Their results showed that 48% of patients in the experimental group completed a new proxy or had a previously completed proxy identified, compared with 6% of controls ( $p < 0.001$ ). For patients with capacity, 22% of patients in the experimental group had a previously appointed proxy agent identified, compared with 6% of controls ( $p < 0.001$ ). Thirty-six percent of patients in the experimental group appointed a proxy decision maker compared with 0% of controls ( $p < 0.02$ ). For patients without capacity, 31% in the experimental group had previously appointed proxies identified compared with 6% of controls ( $p < 0.001$ ). Meier et al (1996) concluded that counselling by hospital patient representatives is an effective way of improving recognition and execution of advance statements in the acute care hospital.

The generalisation of the above findings is limited to urban academic institutions with an office of patient representatives. Larger trials involving a range of patient groups with different diagnoses are necessary to determine the long-term usefulness of this type of intervention.

Brown et al (1999) used written materials only versus written materials and an educational videotape to assess the use of medical advance statements (65). They conducted a population-based ( $N=1,302$ ), randomised controlled trial with three-month follow-up. Their sample members were aged 75 years and older who used a non-profit group model health maintenance organisation. They excluded 55 people who died or dis-enrolled during the study period or were identified by their physicians as blind or cognitively impaired. All participants were mailed a 10-page cartoon-illustrated educational pamphlet on patient choices, a selection of Colorado advance medical directive forms, and a guide to their completion. Six hundred and nineteen participants were also mailed a 20-minute videotape on advance statements. Both groups had access to a study nurse for assistance in completing and placing advance medical directives. Their main outcome measure was the proportion of participants who placed a directive in their medical record for the first time. Analysis of the results showed no difference between the two

groups. Placement rates increased almost identically, from 21% to 35% in the written materials-only group and from 20% to 33% in the group receiving the video tape (95% confidence interval for difference-0.04,  $p=.95$ ). Brown et al (1999) have shown that mailing of written materials increased placement of an advance statement in patients' medical records substantially but the addition of a videotape did not (65). However, a closer analysis of the study reveals a number of limitations, such as the lack of baseline questionnaire responses from which to measure change and the lack of completed questionnaires from 41% of participants at follow up. These two limitations threaten the internal validity of the trial. Another limitation refers to the low rate of viewing in the videotape group. Of the 619 participants randomised to the videotape mailing, only 429 were sent the videotape and a questionnaire on its use three months later. Two hundred and twenty three returned the questionnaire of whom 138 answered the questions about recalling the video and remembered receiving it in the mail, and 89 reported viewing it.

However, even when available, studies produce little evidence that advance statements change treatment or that the patients' preferences are followed. In one study, 175 nursing home patients and family members were interviewed in relation to their preferences for aggressive treatment at the end of life. In 25% of patients, care eventually received was inconsistent with their previously expressed wishes. In most cases patients received less aggressive care than they had requested (53).

A number of prospective and retrospective studies have examined whether advance statements can reduce treatments and costs of hospitalisation (53). They produced mixed results. In a randomised controlled trial of 204 seriously ill patients, researchers provided an advance statement form to patients in the intervention group ( $n=102$ ) at clinic visits or through the mail while the control group received standard care (66). They followed these patients for a minimum of 23 months and measured their medical treatments and costs. Sixty-six percent of enrolled intervention patients (69/104) completed the advance statement. None wrote personal instructions; these patients simply completed the form and designated a healthcare proxy. The study showed no difference on any outcome variable between the intervention and control groups. In addition, within the

intervention group there was no difference between those who completed the advance statement and those who did not (66).

In a retrospective analysis of 336 patients who died at a tertiary medical centre, the definition of an advance statement was expanded to include patients who addressed end-of-life issues before or during hospitalisation (67). Comparisons between patients with and without an advance statement, showed a significant decrease in hospital and physician costs (\$31,200 vs. \$49,900) among the patients with advance statements. In another study, researchers reviewed the final hospitalisations of 474 Medicare patients, looking for any documentation of discussion of an advance statement within the first 48 hours of that hospitalisation (68). Patients who had such discussions sustained less overall inpatient costs (\$30,478 vs. \$95,305). The expanded definition of an advance statement in these retrospective studies creates a problem with interpretation of their results in that evidence may not support advance care planning but rather end-of-life issues.

One of the most important studies in the area of medical advance statements, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), yielded rather disappointing results (69). This multi-centred trial was designed to improve advance care planning. The study was conducted in two phases. The observation phase aimed to identify shortcomings of care and the intervention phase to address those shortcomings. During the two-year observation phase 4,301 terminally ill patients were seen. Forty seven percent of these patients died within six months of study entry. The investigators found poor communication, poor decision-making and poor end-of-life care. They identified five major outcomes for the intervention phase:

- incidence and timing of do-not-resuscitate orders;
- patient-physician agreement on preferences for cardiopulmonary resuscitation;
- days in an intensive care unit , in a coma, or ventilated before death;
- presence of pain;
- hospital resource use.

The intervention phase involved a two-year clinical trial with 4,804 patients randomised to the control and treatment groups. The intervention was the presence of a trained nurse facilitator to provide detailed prognostic information to patients and medical staff, to work with patients and families to elicit and document patient preferences, and to facilitate communication between patients and physicians. The study reported no difference between treatment and control groups in any of the above outcome measures. Although SUPPORT has not yielded positive outcomes, “it has provided the raw data to allow investigators to understand why advance statements never fulfilled their early expectations” (53) (p.37).

In summary, the above studies have shown that after the passage of the Patient Self-Determination Act in 1990 in the USA:

1. Advance statements were recorded by medical personnel more often but were not more frequently completed by patients.
2. The process of recording them did not improve patient-physician communication.
3. They did not change care.
4. They did not reduce hospital resources or save money.

What were the reasons for these negative studies? Following the SUPPORT study, a number of quantitative and qualitative studies were conducted in order to investigate the reasons.

Coppola et al (2001) and Ditto et al (2001) investigated the accuracy of proxy or surrogate decisions made by primary care physicians, hospital-based physicians and family surrogates on behalf of elderly outpatients and examined the effectiveness of medical advance statements in improving the accuracy of these judgements (70;71). The study was conducted in two phases. During phase one, researchers recruited participants from a network of 6 group primary care practices which included 24 primary care physicians. Randomly selected patients 65 years or older were initially contacted by letter introducing the study. Unless patients telephoned to decline participation, trained interviewers telephoned patients to solicit participation. Interviews took place in the patients' homes and lasted for about one hour. A total of 401 patients and their designated family surrogates were



interviewed in phase one. During the interview, patients completed the Life-Support Preferences-Predictions Questionnaire (LSPQ), which measures patient preferences across a broad spectrum of realistic life-sustaining treatment decisions. A subsample (n= 82) of family surrogates was used as a baseline comparison group. As part of phase one, patients and family surrogates were randomly assigned to either a control condition in which they did not complete an advance statement or one of four intervention conditions in which surrogates made predictions after exposure to a patient-completed advance statement (completed with or without discussion with the surrogate). The family surrogates reviewed the patient's advance statement (when applicable), made predictions on the LSPQ regarding patient preferences and rated how confident they were that they accurately predicted the wishes of the patient on a five-point scale. The primary care physicians were asked to complete five proxy decision-making tasks. Thirteen of the 24 primary care physicians completed the tasks for 5 patients. Seventeen emergency and critical care physicians who had no prior experience with the patients and spent 50% of their time working in a hospital setting were contacted by letter to participate. They were provided with basic demographic information about each patient but were blinded to patients' names. They then reviewed the patient's advance statement (when applicable) and made predictions on the LSPQ regarding patients' preferences. After completing the LSPQ with predictions of the patients' preferences, the hospital-based physicians also rated how confident they were that they accurately predicted the wishes of the patient on a 5-point scale and whether they found the advance statement helpful. The results revealed that none of the interventions produced any significant improvement in the accuracy of family surrogates' judgements in any illness scenario or for any medical condition. Discussion of the interventions improved perceived surrogate understanding and comfort for patient-surrogate pairs in which the patient had not completed an advance statement prior to study participation. Consistent with other research findings, primary care physicians were not accurate in predicting their patients' treatment or non-treatment preferences. Their accuracy was not improved by advance statements. Hospital-based physicians making predictions without advance statements had the lowest accuracy. Accuracy and confidence in predictions of hospital-based physicians was significantly improved for some

scenarios using a scenario-based advance statement. The limitations of the study could be summarised as follows:

- The use of hypothetical situations undermines external validity in real clinical situations because it is unclear whether patients' preferences and physicians' predictions would be different if faced with an actual illness.
- Patients and physicians did not discuss the patients' preferences while patients completed the advance statement.
- A relatively small sample of primary care physicians.
- A healthy, well educated, mostly white American sample of patients and surrogates.
- One, relatively brief discussion intervention.
- Prendergast's review (2001) of qualitative studies in this field reveals that terminally ill patients identify five important domains of end-of-life care (53):
  - Avoiding inappropriate prolongation of dying.
  - Strengthening relationships with loved ones.
  - Achieving a sense of control.
  - Relieving burden (e.g. physical care, witnessing death and substitute decision making).
  - Managing pain and symptoms adequately.

These studies have also shown that patients dislike being approached with a checklist of consent for specific treatments instead of having discussions about advance care planning based on their values and experience of illness. In one particular study, outpatient discussions of advance statements were tape-recorded and analysed. The results showed that physicians spoke twice as much as they listened and did not routinely explore patients' values or their attitudes towards uncertainty. A further study also revealed that patients do not believe that their physicians should be at the centre of the discussion about advance care planning and only 9% of these patients preferred their physician to lead the discussion in the case of serious illness. The majority of the patients preferred to discuss treatment preferences with their family or surrogates rather than their physician (53).

### ***Successful implementation of medical advance statements***

There are a couple of successful reports of implementation of medical advance statements (72;73).

A retrospective study of four healthcare providers (in Wisconsin) of 540 deaths over 11 months showed that 85% of participants had advance statements and 95% of these were available in the medical record (72). Most were completed in advance of death (median time between completion and death was 1.2years). Nearly all indicated a willingness to limit life-sustaining therapy, and fully 98% of deaths followed some limitation of therapy. A randomised controlled trial by Molloy et al (2000) showed that systematic implementation of an educational programme about advance statements aimed at elderly individuals in nursing homes, reduced hospitalisations and aggressive care for nursing home patients who did not want that level of intervention (73). These successful reports of implementation of advance care planning have tended to embrace the following principles:

- perceived by service providers as an ongoing process and not as an event designed to produce a product.
- shifts the focus on end-of-life decision-making away from completion of documents toward facilitating discussion about values and preferences.
- shifts the locus of advance care planning away from hospitals and physicians into the community and specifically to the family unit.
- does not assume that the physician is crucial to the process but promotes extensive training of non-medical community volunteers.
- refocuses discussion of preferences away from autonomy toward personal relationships. Instead of asking the patient what he/she wants, they reframe the question as, "How can you guide your loved ones to make the best decision for you?"
- works with hospital and primary care physicians to ensure that completed advance statements are available in patients' charts.

### ***Unsuccessful implementation of psychiatric advance statements***

According to a recent Cochrane systematic review by Henderson and Laugharne (2001), there is no published trial-based data relating to the effectiveness of psychiatric advance statements. Their systematic review aimed to “evaluate the effects of personalised and accessible patient-held clinical information for people with diagnosis of psychotic illness.”

Their search strategy included: electronic searches of AMED (1980-1998), Biological Abstracts (1985-1998), British Nursing Index (1994-1998), CAB (1973-1999), CINAHL (1982-1999), The Cochrane Controlled Trials Register (Issue I, 1999), EMBASE (1980-1999), PsycLIT (1887-1998), Royal College of Nursing Database (1985-1996), SIGLE (1990-1998), Sociological Abstracts (1963-1998) and the Internet (<http://www.controlled-trials.com>). The authors supplemented their searches by making personal contact with the Executive Board of the European Network for Mental Health Service Evaluation.

Their inclusion criteria were:

1. Studies should be randomised or quasi-randomised trials;
2. Studies should have involved adults with a diagnosis of a psychotic illness;
3. Studies should have compared any personalised and accessible clinical information held by the patient beyond standard care to standard information routinely held such as appointment cards and generic information on diagnosis, treatment and services available.

The authors report that the study selection and data extraction was reliably undertaken and that analysis was not possible.

Their main results showed that none of the studies met the inclusion criteria for the review. The authors concluded that: “there is a gap in the evidence regarding patient-held, personalised, accessible clinical information for people with psychotic illnesses. It cannot be assumed that patient-held information is beneficial or cost-effective without evidence from well planned, conducted and reported randomised trials.” (74)

### **The advance statement project in Bradford**

A relevant project in this area is the first phase of the advance statement project in Bradford which aimed to establish a model for advance planning in mental health

services in central England by carrying out two years of extensive development work with service users and mental health professionals in that area (29;75;76). Despite the extensive developmental work, there was very little uptake in the use of advance statements. “Of 70 service users who attended presentations on advance statements only one took up the opportunity.”(75) (p.123) In her report, Andrea Beaver (Research and Development worker) cites the following reasons for the lack of success of the project (29):

1. Advance statements not being incorporated into existing Trust policy, meaning that the statements were easily overlooked. Due to the current legal status of advance statements, accountability for the inclusion of a statement in decisions made about an individual’s care and treatment would ideally come from within Trust policy. This would involve the acceptance of advance statements as a useful tool of communication between service users and service providers.
2. The need for provision of support around the drawing up of an individual advance statement. The development and drawing up of a statement can be time consuming, with relevant information to be gathered and considered before choices can be made. Support with this process could help to bridge the gap between ‘another form to fill in’ and a useful working document that is relevant to individual situations.

Based on these findings the project has been continued with the aim to link the use of advance statements with the Care Programme Approach (CPA) process.

### ***Successful implementation of psychiatric advance statements***

The only example of successful implementation of a form of psychiatric advance statement is the recent single blind randomised controlled trial by Henderson et al (2004) (19). Henderson et al (2004), investigated the effect of joint crisis plans on use of compulsory treatment in psychiatry. A joint crisis plan is a document “developed by the patient together with mental health staff. Held by the patient, it contains his or her choice of information, which can include an advance agreement for treatment preferences for any future emergency, when he or she might be too unwell to express coherent views.” (19) (p 136) Patients were recruited from seven community mental health teams in south London. Eligible patients included those

in contact with their local community mental health teams, who had been admitted to a psychiatric inpatient service at least once in the previous two years and had a diagnosis of psychotic illness or bipolar affective disorder without psychotic symptoms. Excluded from the study were patients who were unable to give informed consent due to mental incapacity or insufficient command of English. Patients were randomised to the intervention and control group and the investigator was blind to patients' randomisation status. Patients allocated to the intervention group were asked to formulate the joint crisis plan together with their care coordinator, psychiatrist, and project worker. The joint crisis plan contained contact information, details of mental and physical illnesses, treatment, indicators for relapse, and advance statements of preferences for care in the event of future relapse. Patients in the control group received information leaflets about local services, mental illness and treatments, the Mental Health Act, local provider organisations, and relevant policies. The primary outcomes were admission to hospital and length of time spent in hospital. The secondary outcome was compulsory treatment under the Mental Health Act 1983. The researchers collected the data from case notes, the computerised patient administration system, Mental Health Act office data and interviews with patients and their carers. Follow up was conducted 15 months after randomisation. Of the 466 patients that were assessed for eligibility, 160 were randomised and analysed (eighty in each group). Statistical analysis showed that the use of the Mental Health Act was significantly reduced for the intervention group (10/80 in the intervention versus 21/80 in the control group). The mean number of days spent on section was also significantly reduced for the intervention group (14 for the intervention group versus 31 for the control group). Finally, the intervention group had fewer admissions (19).

This is the first study that has shown reduction of compulsory admission and treatment in adult mental health services. Although the study has some limitations (for example the rate of hospital admission among the control group was lower than expected which reduced the power of the study to detect a difference in this outcome and only 36% of eligible patients agreed to participate which may reduce generalisability) it offers important insights in future implementation of psychiatric advance statements. As in the cases of successful implementation of medical advance statements, psychiatric advance statements are effective when

they are part of an ongoing process of communication between service providers and patients, they focus the discussion on patients' values and preferences and they shift the locus of advance care planning away from hospitals into community.

## **Potential uses of psychiatric advance statements**

Initially, the use of psychiatric advance statements was recommended to individuals with recurrent psychotic illnesses that were amenable to treatment such as major affective disorders (e.g. bipolar and manic-depression, recurrent mania and psychotic depression) and certain forms of schizophrenia (77). However, the increasingly complex and stressful society we live in resulted in a higher percentage of people who meet the diagnostic criteria for a mental disorder. In the USA, more than one in four adults are diagnosed as developing a mental health problem every year (24). In the UK, the currently proposed revisions to the Mental Health Act 1983 suggest the use of a broader definition of mental disorder and the extension of the use of compulsory treatment in the community (28). The response of the Royal College of Psychiatrists to these recommendations is that the proposals will result in an increase of compulsory detention, stigmatisation and a higher prevalence of mental health problems with enormous societal and financial implications ([www.rcpsych.ac.uk/college/parliament](http://www.rcpsych.ac.uk/college/parliament)).

“The prospect of losing control over the ability to make crucial hospitalisation and treatment decisions should we become mentally ill is a frightening one. This prospect, coupled with the high prevalence rate for mental illness, provides a new incentive to think ahead about mental health treatment possibilities, to understand how the law may respond to mental illness and if possible to avoid unpleasant treatment options and secure more desirable alternatives.” (24) (p. 58)

In view of the above uncertainties, would psychiatric advance statements provide a solution for the possibility of an encounter with mental illness? In the USA, all individuals have a constitutional right to make health-care decisions not only when they are competent, but also when they are incompetent, as long as they indicated in advance the manner in which they wished their right to be exercised or other evidence exists concerning what their wishes would have been. This constitutional right extends to the mental health context as well. Consequently, the creation and implementation of a psychiatric advance statement will overcome the need for formal resolution of treatment disputes and will promote the individual’s autonomy and values. In addition, it may have a significant therapeutic value. For



individuals with no prior experience of mental illness, the possibility of facing mental health problems in the future may lead them to take preventative measures to avoid such problems. Such an example is the case of A.P. presented by Ritchie, Sklar and Steiner (1998).

*“A.P. was a 23 year old woman who had diagnosed herself as bipolar using the Diagnostic and Statistical Manual of Mental Disorders, Third Edition-Revised. She had never consulted a psychiatrist because her family had distrusted psychiatry since her father’s experience with insulin treatment and ECT decades ago. However, she realized that both her hypomanic and depressed phases were becoming more extreme. She wanted to be able to work with a psychiatrist in such a way that she could exercise control over what happened to her. She did not want treatment as yet, although she recognised that she was becoming depressed, but she wanted to know what was available if her depression worsened. Her fear was that her insight was becoming increasingly tenuous when she became depressed and hypomanic. She wanted her psychiatrist to be alert to signs that she was decompensating and to intervene in ways that would have been agreed to beforehand.” (34) (p. 247)*

People who have experienced mental illness may avoid problems they do not want (e.g. excessive spending) by advance planning. Such planning may help them to reflect upon their experiences in light of their most recent hospitalisation and to take responsibility for future decision-making. “Staring into the abyss of mental illness may give people a clearer view of their present reality and an incentive to change it when appropriate and possible, or to find better ways of coping with it. It may also provoke people who suspect that their problems might escalate to obtain treatment early, before their condition gets out of hand. For some people, a little counselling may go a long way, helping them to confront and resolve problems before they become too serious.” (24) (p. 81)

In most mental health settings today, patients’ strongly held feelings about treatment issues are respected and this respect can bring about feelings of relief that can have beneficial effects. When the patient’s concerns about possible treatment and hospitalisation are not taken into account, their stress, fear, anxiety and helplessness may become exacerbated which may in turn affect their process of recovery.

Furthermore, users of mental health services frequently lose initiative and become more dependent and less assertive because of the treatment they receive in psychiatric hospitals. It is generally believed that assuming responsibility for decisions that significantly affect them would be empowering and have expected

beneficial effects. For example, preparing the advance statement document will focus the patient's attention on future goals and how to attain them. The goal-setting effect could be utilized through the process of planning and preparing the instrument. Because the patient's goals would be clearly expressed in writing and executed by the patient during a formal procedure in the presence of witnesses, the advance statement document might provide an effective means of achieving the benefits of goal setting (78). If we hypothesise that mental health care professionals become involved in preparing the document, the process itself may provide the opportunity to engage the patient in treatment and enhance his/her adherence to that treatment. Therefore, patients who are able to choose a course of treatment in advance are likely to feel better about it and be more willing to comply with it, which could maximise the potential for therapeutic success. This has already been empirically supported by Henderson et al's (2004) study (19).

Acting and being treated as self-determining individuals with a significant amount of authority over their own destiny, instead of being powerless and incompetent victims would be therapeutically beneficial to mentally ill patients. Any sensible mental health system would aim to reinstate mentally ill patients to the highest degree possible of community functioning by allowing them to put into effect their decision-making abilities. On the contrary, paternalistic treatment and attitudes encourage powerlessness and victimisation that may lock psychiatric patients in the 'sick role' (20;24).

Individuals who enjoy good mental health and have high self-esteem are also self-determined. They have the ability to plan for the future, envisage future contingencies and produce the desired rather than the undesired ones, and set goals and see them achieved. However, people with psychiatric illness may lack opportunities to enjoy a 'healthy' or 'normal' life style, a realisation that often deepens their feelings of powerlessness, dependence, incompetence and depression (20;24). The development and implementation of a psychiatric advance statement may promote their independence and competence.

Some very disturbed psychiatric patients pose a particular difficulty for mental health professionals during the information-gathering phase of a hospital

admission due to their incapacity. If these patients carried psychiatric advance statements, this could provide mental health professionals with an additional therapeutic tool, by providing them with important information about the patient, his or her treatment history, and his or her treatment preferences and dislikes. This information could be used to make an accurate diagnosis of the patient's condition and eventually lead to shared decision making in relation to an appropriate treatment plan (24).

As already mentioned above, use of psychiatric advance statements might have the potential to avoid formal adjudications of incompetence. Such adjudications are a form of deviance labelling that can cause serious social and psychological damage. Avoiding unpredictable behaviour that alienates others or the stigma of an involuntary admission can only be beneficial for patients.

Lastly, Backlar (1998) suggests that psychiatric advance statements could be used by patients with schizophrenia as tools for giving informed consent or appointing a surrogate decision-maker for future psychiatric research. Given that regulations and guidelines in regard to research involving this population are in most cases insufficient and unclear, a prospective research participant could draft an advance statement with his/her chosen safeguards (79).

To conclude, psychiatric advance statements may have a number of potential benefits to both people who have never experienced a psychiatric problem and those with recurrent mental health problems. The possible beneficial effects include prevention of mental health problem crises, a decrease of involuntary admissions, improved patient satisfaction with services, increased compliance with treatment and less stigmatisation.

## **Potential abuses of psychiatric advance statements**

One of the main issues underlying the implementation of psychiatric advance statements is the avoidance of coercion. For example, how do we ensure that mental health professionals do not coerce patients to accept treatment or force the patients to make psychiatric advance statements by refusing them further treatment if they do not sign the documents?

Some research findings suggest that although no episodes of coercion were noted in patients' charts, 61% of the involuntary patients and 28% of the voluntary patients reported having been coerced (e.g. pressure to select a choice, presenting information to them that they did not wish to receive) during their psychiatric hospitalisation (80;81). This discrepancy between practice and perception may result from a poorly specified conception of what it means to be capable, informed and consenting in widely varying psychiatric circumstances (this will be discussed in the next chapter on mental capacity). It can also result from power inequalities in mental health professional-patient relationships. Psychiatry, in contrast to other medical disciplines has been the subject of criticism (from within and outside the profession) for its role to social control through mental health legislation and sex, race and class biases inherent in psychiatric diagnoses (60;82). Chilling revelations about the confinement of substantial numbers of individuals in mental asylums who opposed the Russian and Chinese communist regimes represent some extreme examples of the use of psychiatry in social control. In this country, voluntary psychiatric treatment became an option after the Mental Health Treatment Act in 1930 (82). The use of psychiatric diagnosis in professional control of the clinical interaction is another potential source of coercion. "Diagnosis locates the parameters of normality and abnormality, demarcates the professional and institutional boundaries of the mental health system, and authorises psychiatry to label and deal with people on behalf of certain sectors of society. As labelling theory points out, the name (i.e., the label) is used not merely to identify and treat a particular problem, but to carry out retrospective interpretation of the person's life. This provides a master status that characterizes the whole person-everything that person does can then be traced to some fundamental flaw. Assignment of a diagnostic label is sometimes used as the legal

basis for provision of social welfare benefits and is often employed in legal matters such as involuntary commitment, the insanity defense, and competence to stand trial. Labelling may also cause difficulties in purchasing health or life insurance and may lead to discrimination in the workplace, school, and the military.” (60) (p. 527) This quote demonstrates that the mental health professional has the power to influence the patient, and will normally do so in order to ensure the patient’s cooperation and adherence in the process of treatment. In addition, the subjectivity and lack of precision inherent in psychiatric diagnosis may undermine the ability of psychiatrists to determine when a behaviour (e.g. excessive spending) is due to relapse or to unwise choice (20). As a consequence, psychiatric advance statements may become instruments of power and control in the hands of mental health professionals. In order to promote a situation of shared power and to ensure that both patients and their mental health professionals are involved in a process of mutual cooperation, a set of safeguards should be in place. Proponents of psychiatric advance statements suggest the following (77;83):

1. Psychiatric advance statements must be legally binding. Under current UK laws, patients and mental health professionals create care plans which involve the patients’ preferences for treatment. However, patients’ preferences and refusals for treatment are not legally binding. As it was discussed in the previous section under the effectiveness of Care Programme Approach, this system may serve professionals’ needs for regular client reviews and clear documentation but patients and carers still feel coerced in Care Programme Approach Meetings. By legally binding patients’ advance agreements and refusals, the state could provide the basis for eliminating feelings of coercion. Unfortunately, the revised draft Mental Health Act 1983 and the new Mental Capacity Act 2005 still deny statutory status to psychiatric advance statements in this country.
2. The patient must be competent when the document is made (this aspect will be fully discussed in the next chapter).
3. Patients must be in remission when the document is made. Being in remission allows the patient to reflect on his/her experience and make choices free of the stress associated with mental illness. But what does it mean in terms of time? When is the most appropriate time for discussing and

drafting such documents? Many would argue that discharge from section, which in many instances coincides with discharge from hospital, is not the best time. In their eagerness to leave the hospital, patients may agree to sign any document. In addition, lack of hospital beds may force treatment providers to discharge patients before they have recovered completely. However, an important advantage of discussing and drafting such documents just before or at discharge is the recent memory of the illness experience and its impact on the patient and his/her family. Provided the patient has recovered sufficiently, is mentally competent and an independent advisor is involved in the discussion and drafting process, this timing should not necessarily lead to coercive practice. Geller (2000) supports this view and states that “state hospitals often do a better job of attending to the rights of the chronically mentally ill population than do other settings with long-stay populations, such as nursing homes. The state hospital might well be the best that is happening in terms of health care proxies for seriously, chronically mentally ill citizens. Finally, a state that has gone to great lengths to keep people out of state hospitals, believes that almost everyone deserves community based services and creates those residential services, the long-stay state hospital population is not terribly different from the long-stay community population since this is a population ever changing between these loci of care. Examining the issues of health care proxies in the former population should give us insight into the issues we might face with the latter population as psychiatric health care proxies move from institutions to communities.” (84) (p.8) A more recent qualitative study by Amering, Stastny & Hopper (2005), suggests that neither being in remission in hospital nor receiving community mental health services is the catalyst for drafting a psychiatric advance statement. Accumulation of different factors (e.g. discussions with mental health professionals while in hospital or in the community and the effect of hospitalisations and/or terminal illness on mentally ill patients and their families), and the individual’s own risk-benefit analysis of possessing the document, seemed to motivate the process of drafting (85).

4. Patients must enter into contracts voluntarily and without coercion. To ensure voluntariness, proponents of psychiatric advance statements suggest that a

third party (e.g. patient representative or lawyer) should participate at the time of execution to assure that the patient's best interests are served (77;86). Close involvement of mental health professionals and service providers in the process of execution of advance statements is not embraced wholeheartedly by either patients and their families or service providers (25;87;88). On the one hand, involvement of mental health care providers may facilitate and increase communication between all parties but on the other hand it may generate conflicts of interest and may increase the time and cost of care (87).

5. Once drawn up, psychiatric advance statements should be valid only for a limited time and subject to review by medical-legal boards. The patient should also retain the right to renegotiate and revoke the directive at any time other than during relapse (20;77;86).
6. A psychiatric advance statement should be clear and specific in order to avoid misinterpretation of its contents and consequently non-adherence. For example, it should specify the signs and symptoms of relapse, indicate what treatments would be preferable, specify the least restrictive alternative and identify a proxy decision maker. In contrast to medical advance statements where individuals may not be able to make specific directives due to lack of experience of the prospective illness, psychiatric patients are in advantage due to previous experience with both illness and treatment (88).
7. Finally, educational interventions and legal aid should be provided to the patients, their families and mental health professionals as well as clear and concise training material regarding the different phases of drafting, implementing and revoking a psychiatric advance statement (88).
8. However, as many authors have pointed out, feasible, procedural safeguards would not eliminate all abuses and mistakes (20;22;77;86). The aim is to balance mistakes against the provision of desired and beneficial treatment.

## **Patients' and mental health professionals' views on the use and effectiveness of psychiatric advance statements**

Two of the aims of the preference for care study were to look at the content of psychiatric advance statements and the patients' and mental health professionals' views on the usefulness of such documents. So far, there has been very little empirical evidence on the content of psychiatric advance statements (e.g. mainly pilot studies). As it was discussed above, one of the main criticisms of such documents is that they will be used by psychiatric patients to refuse all psychiatric treatments leading to 'committable but untreatable patients' that could clog up the hospitals (5;41). During the final part of this chapter, I will cite the studies that surveyed mental health patients' and mental health professionals' views on the use and effectiveness of psychiatric advance statements as well as the findings of the studies on the content of psychiatric advance statements (18;25;85;87;89-92). These studies provide very useful information on the profiles of patients who express an interest in psychiatric advance statements and eventually complete such documents, the profiles of patients who are not positively predisposed towards such documents and the mental health professionals' views and dilemmas towards psychiatric advance statements. These studies will also provide the context against which I will later compare the findings of sectioned patients' psychiatric advance statements. To my knowledge, no other study has looked at the content of psychiatric advance statements of this population before.

In Sutherby et al's study that took place in London, users who wanted to develop 'joint crisis plans' were significantly more likely to be white, to suffer from an affective psychosis, to have a longer duration of illness, and to have made suicide attempts or to have been assessed as being at risk of suicide at some time during their illness (18). The authors report that "although there was no significant difference in the total number of lifetime admissions, those users with less frequent admissions (less than annual admissions) were more likely to consent."(p.58) Regarding the content of the 'joint crisis plans', the authors report that "the three most commonly included elements of the current care plan were mental health problem or diagnosis (95%), current medication (93%) and first signs of relapse ('What happens when I start to become unwell') (93%)." (p. 58)



Statements about what should be done at the first sign of relapse, treatment preferences if a full relapse could not be prevented and advance refusals of a specific treatment (this involved specific drugs because of their side-effects) were the other most common things the users chose to include in their 'joint crisis plans'. The use of the card in a crisis was assessed at 1 month and at 6-12 months follow-ups. The cards were used to provide useful contact numbers and information on current care and treatment, to both formal and informal carers. "The recognition and recording of what has helped or not helped in a crisis and recognition of triggers for relapse or first signs of relapse were reported to facilitate early recognition and appropriate crisis management for both users and carers. The cards appeared to avert unnecessary admission or to facilitate an appropriate early admission." (p. 59) The authors also report that the cards provided an advocacy tool for crisis (18). In terms of the users' views of the process and psychological value of the card, they reported that they felt more involved in their care, more positive and more in control of their mental health problem as a result of developing the card. Two-thirds of users carried their cards with them on most days or every day at the 6-12 months follow-up and 30 of the 37 users said they would recommend the card to other users whilst 17 key-workers would recommend the card to other services (18). One potential problem associated with the drafting of the cards was the stress induced by reviewing the patients' past and future relapses as it was reported by the patients themselves and their key-workers. Another problem identified by the study was that some of the management guidelines and refusals of treatment on the cards of two of the study participants were not followed during the patients' relapse and subsequent admissions. As the authors state, not carrying out the patients' instructions undermined patients' confidence in the study and confidence in their clinical team (18).

Srebnik et al's (2003) study on interest in psychiatric advance directives among high users of crisis services and hospitalisation, suggests that variables significantly associated with interest in creating advance directives were support for the directives by a participant's case manager and having no outpatient commitment orders in the previous two years. Reasons for interest included using

the directives in anticipation of additional crises and as a vehicle to help ensure provision of preferred treatment (89).

Similarly, Backlar et al's (2001) study, provided some useful insights into the reasons patients with schizophrenia opted to complete or not to complete a psychiatric advance directive after the passage of relevant legislation in Oregon (25). Patients who declined to complete the document did so because they either felt it was not necessary and they could manage without it (their doctors or the mental health treatment system could be counted on to look after them) or because they did not receive enough information about it ("It was not talked about enough"). Those who completed a psychiatric advance directive did so because they originally thought they would feel empowered by the process of preparation. However, when the latter group was interviewed at follow-up, they were less enthusiastic and more critical of the official policy that was relevant to implementation of such documents. Patients' mental health providers reported that the psychiatric advance directive had little "impact" on their relationships with their patients. Regarding the content of the directives, this study has showed that patients with schizophrenia did not use the directives as an opportunity to refuse all treatment as it is commonly believed among the critics of such documents and that patients were able to understand the legal concepts associated with the process of drafting, implementing and revoking them. This study also confirmed the finding from the previous ones: when a directive is ignored by outpatient and inpatient clinicians it produces feelings of disempowerment for the patient. Finally, Backlar et al (2001) suggest that "a legal change-although necessary- is an insufficient step to engender social or political change" (p. 437), "without a computerised system for storing and retrieving patients' PAD information, preparing a PAD may do little more than the act of scrawling 'help' on a scrap of paper, stuffing it into a bottle, and hurling it into the ocean."(25) (p. 439)

Furthermore, Amering et al's study (2005) looked at the processes that facilitate and/or impede the drafting, implementation and revocation of psychiatric advance directives (85). This qualitative study showed, that their small sample of individuals with extensive experience with mental health services and crisis interventions had no difficulty grasping the legal concepts associated with

psychiatric advance directives, their participants were drawn to the concept because their wishes would be more likely to be honoured in situations in which they had felt powerless in the past, and by designating a proxy and documenting their preferences they “would improve record-keeping and communication in a system widely seen as inadequate in both...Directives held the promise that participants would not have to explain everything yet again, that they would be believed without having to persuade strangers, that confrontations could be avoided through judicious intervention by their proxy and that appropriate treatment would expedited.” (85) (p. 249) None of the participants viewed advance directives as a blanket means to refuse treatment. Reasons against the drafting of such documents included patients’ fears that the process of drafting “could actually invite the situation it was designed to manage”, “more paperwork, more hassles”, “concerns that the directive may not stand up in court or would be overridden in practice” and distrust in the mental health system to implement this ‘legalistic’ tool. “Finding oneself intrigued by the notion and personalising the concept of an advance directive does not yet commit one to the necessary work of executing it. A number of catalysts can be identified in the accounts of participants who took the step. These tended to operate in cumulative fashion, acquiring persuasive force over time (only a few participants initiated the process soon after the training). Further discussions with mental health professionals clearly motivated some to proceed. Others had been asked about advance directives during their last stay in hospital and now had occasion to act. Many were nudged by terminal illness or psychiatric hospitalisations affecting their families or partners. For others, a reconfigured personal network supplied previously missing others who could be trusted to serve as proxies.” (p. 249) The authors report that their participants varied greatly in the duration of completing an advance directive. Some completed one immediately after training but others took years to mobilise the resources and find the courage to see the process through. In terms of the content of the completed directives, they included preferences for certain hospitals or specific professionals, requests to allow favoured coping strategies (e.g. being left alone at times) and boundary rules (e.g. not being touched by staff without being asked), requests for certain drugs and treatments and reasons for choosing them and people whose company they preferred and others whose presence they could do without. “Much thought was given to ensuring that the advance

directives were feasible and that preferences fell reasonably within the range of options of the mental health system.” (p. 249) These findings were also supported by Sherman’s (1998) study on computer-assisted creation of psychiatric advance directives (92).

As it has already been mentioned in some of the above studies, service providers and mental health professionals when asked, they reported similar concerns to those of the patients in relation to implementation of psychiatric advance statements. Amering et al’s study (1998) suggested that although there is little experience with psychiatric advance statements in Europe, “there is an interest and predominance of positive attitudes towards this legal option among mental health professionals.” (91) (p. 30) In the USA, service providers and mental health professionals are positive towards the concept but they are sceptical, less enthusiastic and critical towards policies of implementation of such documents (25;85;87). The only in-depth qualitative study that examined service provider issues in relation to implementation of psychiatric advance directives to date, is that of Srebnik & Brodoff (2003) that was carried out in Washington, USA (87). The main issues reported by the service providers include the following:

- How crisis services and inpatient staff would know whether a patient had a psychiatric advance directive (PAD) and how the PAD would be available 24 hours a day?
- Whether patients would have sufficient information (e.g. about treatment options especially if PADs are completed outside of a clinical context) and mental capacity to execute PADs.
- How to consider PADs that include treatment preferences inconsistent with clinical standards of care.
- What would be the role and the level of the service provider in PAD execution.
- How would service providers be certain that the information in PADs would be current?
- How would service providers make sure that the information in PADs would not be redundant with information gathered upon admission?

- What would be the ideal document for capturing the patients' preferences adequately in a reasonable amount of time?
- What was the relationship of PADs to involuntary treatment statutes?
- What were the circumstances under which PADs come into effect or are 'activated'?
- Srebnik and Brodoff (2003), suggest that "administrators who seek to remove barriers to staff using and honouring psychiatric advance directives should also provide specific training to staff on the implementation issues presented above, so that questions may be answered to the extent possible before staff are faced with the documents in their work." (87) (p. 266)

In summary, the few studies that are cited in the last part of this chapter have shown that psychiatric advance statements are not used by patients as a blanket means for refusing all treatment as it is commonly believed by the critics of such documents. Patients who complete such documents do not compromise mental health professionals with either the content or the style of the document. When patients' advance statements are not honoured, it results in patients feeling disempowered and distrustful towards the mental health care system. In terms of the mental health professionals' views on such documents, most of the studies showed that the majority of them are positively predisposed towards advance statements but sceptical and critical about the clarity of existing guidelines for implementing them.

## **Chapter summary**

This chapter has explored the changes in psychiatric services during the last half-century that led to users' autonomy and self-determination and the rise of psychiatric advance statements. An overview of the different labels attached to patients' preferences for future medical and psychiatric care should they lose mental capacity, provided the rationale for using the generic term psychiatric and medical advance statements throughout this thesis. This part has been followed by a historical overview of the development of advance statements and their legal status in the United States of America, the European Union and Britain. The legal debate on advance statements was then followed by the philosophical debates underlying both medical and psychiatric advance statements. The research on effectiveness of the medical and psychiatric advance statements has been reviewed and the potential uses and abuses of psychiatric advance statements have been outlined. Finally, the few studies that looked at the content of psychiatric advance statements, the patients' and the mental health professionals' views on the effectiveness of such documents were described. In the following chapter the concept of mental capacity and its relation to psychiatric advance statements will be discussed.

## CHAPTER 2

# MENTAL CAPACITY

### Introduction

“Capacity is a mental construct that deals with an individual’s rationality and comprehension of reality. Without capacity there is no choice or freedom. Capacity is the hinge on which freedom swings.” (93) (p.3) Capacity conforms to the rational-cognitive model usually adopted in legislation and is not determined by the quality or effect of individuals’ choices. “The Law Commission Report recommended that there should be a statutory definition of capacity, and suggested: A person should be regarded as unable to make a decision if at the material time he or she is:

- Unable by reason of mental disability to make a decision on the matter in question
- Unable to communicate a decision on that matter because he or she is unconscious.”(45) (p. 13)

In this chapter the issues related to mental capacity in general and its relation to psychiatric advance statements in particular will be explored. The terms mental capacity and competence will be used interchangeably.

## **Global, domain-specific and decision-specific capacity**

Historically people were considered either capable of making all decisions or none, a belief that worked well for the completely competent and the completely incompetent people (e.g. those in a coma). However, this global evaluation of capacity does not cater for the individuals who lie between these two extremes. As a consequence, the global definition of capacity needed refinement and the domain specific capacity has been introduced (93). According to this paradigm capacity can be divided into a number of domains:

- Capacity to make a will
- Capacity to make a gift
- Capacity to litigate
- Capacity to enter a contract
- Capacity to vote
- Capacity to enter personal relationships
- Capacity to consent to and refuse medical treatment
- Capacity to create advance statements
- Capacity to consent to research

Domain specific capacity recognises that people may have capacity in some domains such as health care but lack capacity in others (e.g. managing their finances and/or entering personal relationships). However, even within each domain there is a hierarchy of decisions ranging from complex to simple ones. Some individuals may have the capacity of making simple decisions within a specific domain but not the difficult ones (93). The following table gives an example of the hierarchy of decisions in general medicine.



<b>Difficult</b>	Carotid Endartrectomy Cancer treatment Curative vs. palliative surgery, chemotherapy Coronary artery bypass Elective joint replacement
<b>Moderate</b>	Cholecystectomy Anticoagulant treatment Pacemaker
<b>Simple</b>	Course of antibiotics Influenza vaccination Vitamin replacement Blood/urine test

**Table 5: Hierarchy of decisions in a single domain (adopted by Molloy, Darzins, Strang, 1999)**

In the following pages, the legal, clinical and emotional components related to capacity will be explored within the health care domain and in particular the capacity to draft and revoke psychiatric advance statements.

## **The legal aspects of capacity**

In this country, whether an individual has or lacks capacity to make treatment decisions is ultimately a question for a court to answer (27;94). In practice though, doctors, psychologists, social workers and others make capacity assessments every day of the year and very few cases result to courts. However, incorrect assessments of incapacity will provoke unnecessary court procedures, with subsequent delays in the patient's treatment, expense and time lost for clinical care. Truly competent patients whose decisions are overridden can suffer substantial damage to their sense of self and freedom because they will be deprived from their civil liberties. Mistaken findings of competence leave patients who have inadequate decision-making powers without the protections afforded by substitute decision makers and leave health and mental health carers open to potential legal liability (95). The latter has been illustrated by the well-publicized cases of Bournemouth in the UK and Zinermon v. Burch in the USA (96;97). In Bournemouth case, Mr L who suffered from severe autism and severe learning difficulties was informally admitted to hospital simply because he didn't resist the action although he was clearly incompetent to give informed consent. In Zinermon v. Burch case, a psychotic patient Mr. Burch was allowed to sign legal documents for voluntary hospitalisation and treatment although he was clearly unable to give informed consent (96;97).

The legal process of capacity assessment follows certain general rules. An individual is presumed to have mental capacity until the contrary is proved. Once it has been proved that someone lacks capacity, this finding continuous to remain valid until the contrary is proved. For people with fluctuating periods of capacity and incapacity the law provides the term "lucid interval" which means that if they sign a document during this "lucid interval" it might be valid. The burden of proof that someone is lacking capacity rests with the person who is making the allegation and the standard of proof is based on the balance of probabilities which applies in civil proceedings (27;94;98).

### ***Capacity to consent to or to refuse medical treatment***

In general medicine in the UK, health professionals can not legally examine or treat any adult without his or her valid consent unless treatment is required under

the Mental Health Act 1983. The law requires the doctor who is responsible for proposing and/or delivering treatment to provide the patient with an account of the benefits, risks and possible alternatives of the proposed treatment and to judge the patient's capacity to give a valid consent (94;98). The following table outlines the criteria for inability to make decisions according to the Mental Capacity Act 2005 (27).

<b>3 Inability to make decisions</b>
(1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable— 25 (a) to understand the information relevant to the decision, (b) to retain that information, (c) to use or weigh that information as part of the process of making the decision, or 30 (d) to communicate his decision (whether by talking, using sign language or any other means).
(2) A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, 35 <i>visual aids or any other means</i> ).
(3) The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make <i>the decision</i> .
(4) The information relevant to a decision includes information about the 40 reasonably foreseeable consequences of— (a) deciding one way or another, or (b) <i>failing to make the decision</i> .

**Table 6: Criteria for inability to make decisions. Mental Capacity Act 2005**

The Act also states that people who have no capacity to consent to or refuse to treatment can be treated in their best interests and that force can be used to deliver the care and treatment as long as it does not exceed the force needed to keep someone safe in this way (27).

The test of capacity to consent to or refuse medical treatment differs from other tests of capacity not only in terms of the actual criteria of assessment but also in terms of the possibility of conflict of interest between the patient and the doctor who assesses capacity and delivers medical treatment at the same time. In order to

avoid such potential conflicts of interest the new Mental Capacity Act 2005 proposes a number of safeguards such as the appointment of an independent consultee or advocate, the appointment of a lasting power of attorney (allows people to say who can decide for them if they cannot decide for themselves at some later time in the future) and a court appointed deputy (if someone who lacks capacity has not chosen anyone to look after their affairs, the Act will let the Court of Protection choose someone to make decisions about money or health and social care or both). In addition, the Act gives adult individuals the right to refuse medical treatment and to create advance refusal documents with treatments they wouldn't want to receive if they become incompetent in the future. The test for capacity to make an advance statement or an advance refusal is similar to that for capacity to make a contemporaneous decision (98).

#### ***Capacity to consent to or to refuse psychiatric treatment***

According to the report of the expert committee on the review of the Mental Health Act 1983, two of the main aims of the revisions, are the promotion of patient autonomy and the end of discrimination in the treatment of mental illness. The expert committee also reported that “whatever the precise scope of a mental health act it must primarily be seen as a health measure and must be consistent with the professional ethics of the health services. This is not to deny the importance of public protection but to place it within the appropriate context within which it can best be promoted.”(28) (p. 18) With this principle in mind, some of those who commented on the revisions of the Act suggested that in order to promote patient autonomy and non-discrimination, patients with mental disorders who retain the capacity to make treatment choices and refuse the treatment for their mental health problems proposed by their doctors, should not be treated whatever the consequences for the patient. Only those who lack capacity should be treated without consent under the mental health act. As for the patient with a mental disorder who refuses treatment and poses a serious risk to others, he or she should be dealt with through the criminal justice system. However, that approach has not been accepted by the expert committee that suggests the safety of the public should outweigh individual autonomy. In other words, a person with mental disorder that can be treated should be treated under the mental health act.

The Committee adopts the reasoning that “mental disorder unlike most physical problems may occasionally have wider consequences for the individual’s family and carer, and very occasionally for unconnected members of the public affected by the individual’s behaviour, acts and omissions.”(28) (p. 19) In contrast to its acclaimed principles of patient autonomy and non-discrimination, the report of the expert committee on the review of the Mental Health Act 1983 embraced a broader definition of mental disorder and permitted detention on the basis of deterioration of mental disorder regardless of the patient’s capacity. The latter has provoked a lot of criticism towards the new revised Act not only from the psychiatric establishment but also from national user groups (11;99-101). ([www.rcpsych.ac.uk](http://www.rcpsych.ac.uk); [www.mind.org.uk](http://www.mind.org.uk)) To justify detention of mental health patients who retain capacity under the Mental Health Act 1983, the expert committee suggested “the need to develop a very careful definition of capacity.”(28) (pp 88-89) (See Table 7)

7.5. ....Thus we propose a broad model of incapacity which accepts that a person may lack capacity where, although intellectually able to understand and apply the information, that person nonetheless reaches a judgment which s/he would not have reached in the absence of the disorder. Such a judgment can be said to be primarily the product of the disorder and not to reflect the person’s true preferences. Paragraphs 3.16 and 3.17 of the Law Commission’s Report capture the essence of what we wish to recommend. Thus a person lacks capacity to consent to care and treatment for mental disorder if at the time when the decision needs to be made the mental disorder is such that, either:

**i. ‘he or she is unable to understand or retain the information relevant to the decision, including information about the reasonably foreseeable consequences of deciding one way or another or failing to make the decision.’ (para 3.16);**

**or,**

**ii. ‘he or she is unable to make a decision based on the information relevant to the decision, including information about the reasonably foreseeable consequences of deciding one way or another or failing to make the decision.’ (para 3.17)**

**Table 7: The definition of mental capacity outlined in the report of the expert committee on the review of the Mental Health Act 1983**

However, the apparent breadth of the test has caused a lot of anxiety among those consulted by the Law Commission and those who responded to the committee’s Draft Proposals. These anxieties include:

- the fear that it will be up to doctors alone to decide whether the decision reflects a true choice,
- that the tendency will be to equate incapacity with failure to agree with the doctor,

- that incapacity will become indistinguishable from lack of insight,
- that the test is dangerously subjective and
- that it will lead to an increased use of compulsion (28).

In order to address these concerns, the committee emphasized that there will be a presumption in favour of capacity and that it will be for the tribunal to decide rather than the doctor. Furthermore, the committee provided four examples that could help mental health professionals to apply the test in practice:

- To what extent is the decision a ‘product’ of the disorder? In answering this, account should be taken of whether the decision conflicts with the individual’s views, previously expressed or demonstrated at a time when s/he had capacity.
- Imprudence does not on its own amount to lack of capacity.
- It is appropriate to take into account the individual’s ability to understand the reasonably foreseeable consequences of a decision.
- Capacity is a sliding scale - it may be easier to establish lack of capacity where the consequences of the decision to be taken are more onerous: a patient must have capacity ‘commensurate with the gravity of the decision he purported to make’ (Re T [1992] 2 FCR 861 at 874; Re MB [1997] 2 FCR 541 at 549).  
(28)(p. 90)

### ***Patient's capacity to execute & implement psychiatric advance statements***

As it was mentioned in chapter one, in this country, psychiatric advance statements will not be given statutory approval. Therefore, neither the report of the expert committee on the review of the Mental Health Act 1983 nor the Mental Capacity Act 2005 provide any guidelines for the assessment of capacity for drafting and implementing such documents. However, the distinction between persons with and without capacity to make decisions and the option to create a psychiatric advance statement may offer a useful avenue for legislation appropriate to community treatment since these documents could offer a means of integration of autonomy and the initiation of voluntary treatment at an early stage of relapse (102). The feasibility of psychiatric advance statements depends on whether it is possible to assess capacity. According to Halpern and Szmukler (1997) psychiatric advance statements involve three capacity-related decision points concerning:

- their making,
- applicability (loss of capacity triggering the psychiatric advance statement) and
- revocation.

### ***Assessing competence when making a psychiatric advance statement***

#### **Comprehending and retaining treatment information**

Here the psychiatric patient should be in a position to understand the facts associated with the nature of his/her illness as well as the ones associated with the purpose and likely consequences of an advance treatment decision. However, the complicated nature of mental illness makes comprehending and retaining treatment information difficult for the psychiatric patient. In addition, the multidisciplinary nature of hospital care and the way treatment information is passed to the patient may confuse matters even more. "Sufficient understanding to make treatment decisions does not mean that a patient has to share entirely the medical view of his or her condition and treatment as was seen in the case of *Re C.*" (102) (p. 324)

### **Believing the treatment information**

The nature of mental illness, psychodynamic factors, the way the information is presented to the patient, the stability of the patient's mental status and effects of the setting in which the different treatment options are discussed play an important role in determining whether or not the patient believes the different alternatives (95). A clear-cut assessment of capacity or incapacity is not always possible and in non-emergency situations more than one consultation may be needed in order to assess whether or not the patient understands and accepts the information.

### **Weighing evidence and arriving at a choice: "the true choice test"**

#### **B v. Croydon Health Authority**

*Miss B suffered from borderline personality disorder and was detained under s.3 of the Mental Health Act (1983). She had been sexually abused in childhood first by her grandfather and later by a lodger. When her grandfather died in 1990 it provoked acute guilt feelings and feelings of low self-esteem. In 1991 she was involuntarily admitted to hospital. During her hospital admission she started self-harming. At first she tried to cut herself and later she attempted burning. When all opportunities for self-abuse were removed by staff, she began to starve herself. By the end of December 1993 her weight was down to under 5 stone and she was in danger of dying. In March 1994 Miss B wrote a letter asking to have therapy for her underlying wish to harm herself. Her letter went unanswered and the doctors suggested nasogastric tube feeding instead. Miss B refused the intervention and consulted solicitors. Her case reached the courts in June 1994.*

*In court Miss B gave coherent evidence that her refusal to be tube fed was based on the feelings that the process would rekindle. She stated that such a process would trigger her feelings of being sexually abused. The consultant psychiatrist who gave evidence on Miss B's behalf stated that her disorder brought with it an inescapable distortion of cognition. He went on to give the court an analogy: "mental illness is like the cherrystone in the ice cream, its symptoms may be detached and removed. Borderline personality disorder, by contrast, is like raspberry ripple; it is the person" (A one day conference on Mental Health Law, p. 10)(103). He questioned whether lawyers and doctors have the right to take away such person's coping mechanism. The judge Mr Thorpe (the same judge who had decided Re C) held that Miss B was competent at common law to refuse to be tube fed. However, he also held that s.63 of the Mental Health Act overrode Miss B's autonomy. He ruled that she could be force fed against her wishes because such treatment constituted "medical treatment for mental disorder". Section 63 of the Mental Health Act 1983 provides that: "the consent of a patient shall not be required for any medical treatment given to him for the mental disorder for which he is suffering, not being treatment falling within section 57 or 58 above, if the treatment is given by or under the direction of the responsible medical officer." (A one day conference on Mental Health Law, p.11) (103)*

In contrast to Re C (cited in introduction), where his refusal was related to a physical condition unconnected with his delusional beliefs, Miss B's refusal in B v. Croydon Health Authority, was not a true choice but a choice immediately related to her mental disorder (her disorder bound her to refuse food). The legal procedure in the case of Miss B was confusing in terms of granting a patient capacity to refuse treatment but denying the truthfulness of her choice. The



magnitude of the intrusion on a patient's autonomy that is represented by the consequences of a finding of incompetence and the impact of allowing a competent patient to refuse potentially life-saving treatment argues for a cautious and comprehensive approach to evaluation of capacity.

***The loss of capacity triggering an advance statement***

Loss of capacity is usually a gradual process that poses difficulties in defining the point at which a psychiatric advance statement may be triggered. Clearly drafted psychiatric advance statements that cover the particular situation(s) that has arisen sufficiently will help overcome the need for court involvement. Usually previous experience of a recurrent mental illness with loss of capacity should make it easier to draft applicable psychiatric advance statements (102). An example might be "when I have spent more than £2,000 my psychiatric advance statement is to apply."

***Revocation of an advance statement***

Halpern and Szmukler wrote: "The test of capacity for revoking a psychiatric advance statement has not yet been considered by the English courts. The Law commission comments that whether people have the capacity to alter their psychiatric advance statements is inevitably a question of fact and evidence in any particular case. If the required capacity of revocation were to be less than that which was necessary to make the binding treatment decision, then a psychiatric advance statement might be revoked by a relapsing patient just at the point at which, when well, the person had previously considered it should be implemented.....Previous experience of precisely the same illness and subsequent loss of capacity should make it easier to draft criteria highly specific to the individual and with the individual's endorsement." (102) (pp. 325-326)

To avoid coercion a number of safeguards should be in place such as independent witnesses and advocates and the possibility to appeal in cases of dispute.

Assessment of capacity determines the right of a patient to draft, implement and revoke a psychiatric advance statement, to refuse hospitalisation and treatment and to receive legal protection. The discussion so far, has established that assessment of capacity is not a black and white issue but closely related to the decision that needs to be made. The tests for capacity have been established by law and although the assessment of capacity is ultimately a legal matter, in every day life doctors and other health professionals are the ones who have to assess the functional aspects of capacity. In the following pages the clinical issues underlying the assessment of capacity will be considered.

### **Clinical approaches to capacity**

Clinicians use scientific/medical knowledge and an examination of the patient to form a medical diagnosis that determines whether or not the patient's understanding and judgement are in accordance with people who do not suffer serious psychiatric illness. This assessment may support a further judgement of competence or incompetence and decisions concerning its consequences. Although competence is a legal concept, it is usually the clinician's judgement that is critical in determining whether a patient is regarded as competent or incompetent to carry out the activity at hand. Consequently, the legal and medical matters are very closely linked. Kitamura et al (1999) examined the question of who is better equipped to judge a patient's competence (the lawyer or the doctor) (4). They compared the evaluation of patients' competence by mental health professionals, lawyers, medical and legal students. They concluded that persons in the legal profession in comparison with physicians find a greater level of decision ability in the same patients. It was also shown that non-clinicians do not perceive the pathological aspects of certain mental health disorders such as paranoia. Their finding is not very helpful because the confusion surrounding the question whose determination of competence would be used (the practitioner's or the judge's ?) to predict the patient's future behaviour in cases of conflict is not resolved. Furthermore, the study took place in Japan where psychiatry is very conservative and rather legalistic and has not been replicated in other countries which makes it susceptible to cultural biases.

Another study by Markson et al (1994) that surveyed various medical specialists (internists, surgeons and psychiatrists) suggested that although most physicians knew the standards of competence, they applied them incorrectly both at a theoretical and practical level (104). As for the psychiatrists they answered correctly only half of the time about whether a demented patient could be considered competent. Markson et al (1994) suggested that “judges must be exceedingly careful in evaluating medical and psychiatric testimony in competency proceedings. In particular, judges should not rely upon-and perhaps should not even ask for- expert witnesses’ conclusions regarding patient competence.”(104) (p. 1079)

In any case, in most countries today, the judges are the ones who ultimately decide whether a patient is competent or not and attempts are made to educate both doctors and lawyers on the legal tests of capacity and how to use them in clinical practice (94).

The traditional approaches to the assessment of capacity based on the ‘outcome’ of the individual’s decision-making (e.g. refusal of a particular treatment) and on his/her ‘status’ (or diagnosis) have been rejected on both empirical and conceptual grounds. Instead a functional approach is now preferred. As the study of Kitamura et al (1999) showed, both clinicians and lawyers agree that capacity is multidimensional including four factors (4):

- Understanding of the treatment
- Insight
- Autonomy and coercion
- Best interest and recovery.

Although the functional approach is used in current clinical practice, it is associated with many difficulties. It is time consuming, legal and clinical standards vary and most importantly there is no certainty about the threshold at which incompetence should be judged (105). Adequate assessment should involve

compound measures of evaluation that are not hierarchical but complementary and should reflect the complexity and the risk of the decision (106).

In the literature there are a number of semi-structured interviews, recognition tests (e.g. patients are asked questions about a short essay on treatment rights) and clinical vignettes that assess both capacity to sign informed consent for admission/treatment and capacity to complete an advance statement. Review papers on these instruments emphasize that each of these tests investigates certain aspects of the problem but none is either complete or sufficient for a given patient (107).

One of the first instruments developed, was the Hopkins Competence Test (HCAT), by Janofsky et al (1992), which assesses the capacity of patients to make treatment decisions or to draft advance statements (108). The questionnaire was administered to both medical and psychiatric patients. The instrument consists of short essays describing informed consent and the durable power of attorney followed by six comprehension questions about the material presented in the essay, all formatted at 13<sup>th</sup>, 8<sup>th</sup> and 6<sup>th</sup> grade reading levels. The questions try to establish the types of information a patient would need in order to make an informed decision and also the appropriate time for drafting advance statements. In addition to the HCAT, a mini-mental state exam (MMSE) was performed as well as an independent exam by a forensic psychiatrist. The study showed the inter-rater reliability for the HCAT to be high. The HCAT scores were distributed over a range of 1-10, with a score of less than four strongly correlating with the forensic psychiatrist's assessment. The MMSE was found to be neither a sensitive nor a specific screen for establishing competence (108). However, another study by Molloy et al (1996) compared the standardised mini mental status examination (SMMSE) with a panel's competence assessment (the panel consisted of a health worker, a lawyer and an ethicist) and a geriatrician's assessment to evaluate the capacity of 96 older patients to draft an advance statement and found that the SMMSE accurately differentiates people who can learn about and ultimately complete an advance statement from those who can not (109). To conclude, the HCAT may be a useful tool for screening large numbers of patients because it only takes ten minutes to administer (while the assessment conducted by the forensic

psychiatrist took approximately 45 minutes) but more studies are needed in order to test the validity and reliability of the instrument. The study by Janofsky et al (1992) used only a small number of patients to test the instrument (n=41). The sample was randomly selected but selected from patients hospitalised in an urban teaching hospital.

The most frequently quoted and used tool to date, is the MacArthur Competence Assessment Tool for Treatment (MacCAT-T), a semi-structured interview designed to evaluate patient's competence (106;107;110-113). The authors compared the responses of acutely ill psychiatric patients diagnosed with psychotic disorders (n=75) with those of patients diagnosed with depression (n=92) and ischemic heart disease (82). This population was in turn compared to a matched group of the general population not known to have any psychiatric illnesses (111-113).

The authors developed three instruments to assess abilities related conceptually to the four legal standards that are used to determine patients' capacity to consent to treatment: understanding, appreciation, reasoning and the ability to express choice. They operationalised the relationships between the legal standards and relevant psychological functions in the following ways (111-113):

1. For abilities related to understanding, they measured the patients' ability to demonstrate comprehension of information about the nature of the disorder, the nature of the treatment that is being recommended and the benefits and risks associated with it, by paraphrasing or recognising items of information (related to one's own disorder) after they are presented in an informed consent disclosure.
2. They operationalised appreciation as acknowledgement of illness and the potential value of treatment or acknowledgement of these things after illogical premises underlying initial non-acknowledgment were challenged.
3. Reasoning was operationalised by one's demonstration of several problem-solving abilities when faced with a decision about treatment for a disorder.
4. The ability to communicate a choice was operationalised as the person's ability to select a treatment option in a decision-making task.

They used three instruments to measure the above abilities:

1. Understanding Treatment Disclosures (UTD) involves a standardised presentation of five paragraphs (of two-to-five sentence each) of information corresponding to content required for informed consent for each of the three conditions (schizophrenia, depression, ischemic heart disease) which were worded to meet a 7<sup>th</sup> to 9<sup>th</sup> grade reading criterion. The UTD provides two types of disclosure: uninterrupted (e.g. presentation of all five paragraphs prior to assessment of understanding) and element disclosure (e.g. presentation of each paragraph separately, with understanding assessed following each paragraph). The UTD assesses understanding by using paraphrased recall and recognition and takes about 25-30min to administer.
2. Perceptions of Disorder (POD) is a standardised interview that includes nine stimulus questions and has two parts: measuring non-acknowledgement of one's disorder (NOD) and non-acknowledgement of the potential value of treatment (NOT) even when successful treatment is likely. The test takes between 10 to 20min to administer.
3. Thinking Rationally About Treatment (TRAT) includes the presentation of a vignette describing a hypothetical patient's mental or medical illness and the description of three treatment alternatives as well as their benefits and risks, presented orally and on printed cards. Within this scale the patient's ability to express a choice (EC) is also measured by a single item. After the presentation of the vignette the participants are asked which of the three treatment options they would recommend to the hypothetical patient. This instrument requires 25-30min for administration.
4. In addition to the above measures, the researchers also used the Beck Depression Inventory, three subtests of the Wechsler Adult Intelligence Scale-Revised (vocabulary, similarities and digit span) and the Brief Psychiatric Rating Scale (113).

Grisso et al (1995) report good reliability and internal consistency for the three instruments. They also suggest that the measures have reasonable sensitivity because very few people who would be judged by a court to be incompetent would perform well on all of the measures. However, they caution that specificity is uncertain because low scores on one or more of the measures may not be highly predictive of legal determinations of incapacity (112).

In terms of their main findings, Grisso & Appelbaum (1995) reported that all patient groups (as well as non-patient groups) performed better when information was disclosed to them part by part than when disclosed as a whole (uninterrupted disclosure). They also reported that on all three capacity measures (UTD, POD and TRAT) mentally ill patients showed deficits in performance more often than did medically ill patients and their non-ill control groups. “Indeed, when the most highly impaired subgroups were identified on each measure, they were composed almost entirely of patients with mental illness.” (112)(p. 169) The authors report that regardless the overall lower scores of the mentally ill groups, there was considerable heterogeneity within and across these groups. Impairments in performance were more significant and more consistent across measures for the schizophrenia patients than for depression patients. However, the majority of patients with schizophrenia did not perform more poorly than other patients and non-patients, it was a minority within that group that lowered the mean performance. Although that minority within the schizophrenia group was not distinguishable on the basis of other demographic, mental status or patienthood variables, it did manifest greater severity of psychiatric symptoms, especially those of thought disturbance (112). This finding suggests that a diagnosis of schizophrenia should alert clinician’s attention to the possibility of deficiencies in abilities related to mental capacity, but the diagnosis itself is only moderately related to serious deficits in those abilities. Further screening of at risk cases should be performed. The authors caution that in reality the proportion of patients (with both mental and medical illnesses) who have serious deficiencies in decisional abilities to consent to treatment is larger than their finding suggest. This is so due to the fact that some patients were not enrolled to the study because their doctors believed they were too acutely ill to participate (112).

In summary, although the instruments were found to be valid in many respects, they may not be feasible for every day use by clinicians. The standardised text may be difficult to adapt to every case; the tests do not give an overall rating; the length of administration exceeds an hour and the scoring methods are bulky (106;107;110;112). To overcome these problems, Grisso et al (1997) developed the MacArthur Competence Assessment Tool for Treatment Decisions (MacCAT-

T) which uses features of the research instruments described above, assesses abilities related to each of the four legal standards for mental capacity, is valid and reliable and requires 15-20min administration (114). However, more studies are needed in order to determine the degree to which different clinicians elicit similar responses from patients.

In general, the different measures of capacity assessment have shown that recognition rather than recall of information is preferable in capacity assessment because verbal disabilities have been found to correlate with lack of capacity in schizophrenia and Alzheimer's disease (106). These tests have also suggested that a proportion of psychiatric patients have deficient decision-making skills. These patients usually suffer from organic syndromes, psychosis and depression (106;111-114). In schizophrenia, incapacity has been found to correlate more closely with cognitive impairment than symptoms but can be restored by using educational intervention and cognitive and behavioural strategies. Delirium is a serious medical condition, which can disrupt decision-making capacity by altering cognition and motivation and increasing anxiety. In order to restore capacity, medical interventions are directed towards resolving the underlying causes of the delirium.(106;111-114).

To conclude, the evaluation of competence to make treatment decisions is a complex issue that requires the implementation of clear legal and clinical criteria. Although the existing measures of competence assessment pose a number of problems including their inadequacy to address specific legal thresholds for capacity, they do have several advantages over the abstract application of the legal standards in clinical practice. The most important advantage of using a scale such as MacCAT-T, is when a clinician is faced with an ambiguous case rather than a clear-cut one. Using the scale will ensure that the clinician has covered the full range of abilities that should be considered in making competence judgements, it will provide documentation of the clinician's care in informed consent disclosure and inquiry, it will help structure the clinician's reasoning about mental capacity and finally it will equip clinicians with evidence they could use to explain to third parties (e.g. a surrogate or court) how the final clinical judgement was made.



## **Emotional components of mental capacity**

In the previous pages, the concept of mental capacity to consent to treatment and to draft psychiatric advance statements has been defined as the cognitive ability to understand the information relevant to a decision, to retain that information, to use or weigh that information as part of the process of making the decision, and to communicate the decision (whether by talking, using sign language or any other means). The MacArthur Study operationalised these criteria and created the first valid and reliable compound measure of mental capacity for use by clinicians (111-114). However, Louis Charland in his paper on Competence to Consent and Emotion, is the first author to challenge the mere underlying cognitive basis of measurement of mental capacity and in particular the criteria of ‘understanding’ and ‘appreciation’ of the MacArthur Study (115). Although Charland does not reject the cognitive criteria, he suggests that assessing mental capacity requires additional emotional capacities. He believes stripping the emotional components off mental capacity assessment is due to the old fashioned idea that emotions cloud our rational decision-making abilities and that logic is in conflict with feeling. He argues, that this non-cognitive approach to emotion does not take into account the modern psychological theories of emotion which suggest that “emotions are cognitive in virtue of their capacity to represent, that is, to ‘stand for’ or ‘be about’ features in the world. Indeed, there is now sufficient evidence to advance the hypothesis that emotions may form a specialized representational information processing system of their own, like vision, say or language.” (115) (p. 71) Charland borrowed his arguments from Damazio’s, de Sousa’s and Lazarus’s work on the rationality of emotion (116-119). Damazio (1994) a behavioural neurologist, describes case histories of patients with injuries to the inferior and medial portions of the frontal lobes who score very highly on intelligence, neuropsychological and personality testing as well as on more sophisticated tests of decision making which require them to generate options for action, display awareness of consequences, identify efficacious means of achieving social goals, predict social consequences of events and make moral judgments. However, these patients cannot use their emotions in every day decision making at all. “But now I had before my eyes the coolest, least emotional, intelligent human being one might

imagine, and yet his practical reason was so impaired that it produced, in the wanderings of daily life, succession of mistakes, a perpetual violation of what would be considered socially appropriate and personally advantageous. He had had an entirely healthy mind until a neurological disease ravaged a specific sector of his brain and, from one day to the next, caused this profound defect in decision-making. The instruments usually considered necessary and sufficient for rational behavior were intact in him. He had the requisite knowledge, attention, and memory; his language was flawless; he could perform calculations; he could tackle the logic of an abstract problem. There was only one significant accompaniment to his decision-making failure: a marked alteration of the ability to experience feelings.” (119) (pp. xi-xii) According to Damasio, emotions provide us with an efficient mechanism for integrating information that is crucial to our every day decision-making. Without emotions we wouldn’t be able to integrate a huge amount of situation-specific information and life experiences simply because the brain cannot deal with so many pieces of data at once. ‘Gut feeling’ is the glue that keeps together all the pieces of information necessary for competent decision making (119). This is the premise on which Charland based his argument about the incomplete nature of the “understanding” component of mental capacity assessment (115).

In addition, de Sousa (1987) and Lazarus (1994) suggest that emotions are the source of our most basic goals, values and preferences because they motivate us to action and help us to explain and predict behaviour. Charland borrows Lazarus’s (1994) theory of the motivational and appraisal components of emotion to challenge the “appreciation” component of mental capacity assessment. According to Lazarus, (1994) emotions have a primary and a secondary appraisal component. Primary appraisal addresses whether and how an encounter is relevant to our well-being (e.g. is the person in front of us angry?). Secondary appraisal refers to our evaluation of the options and resources for coping with the situation and future prospects (e.g. If the person in front of us is angry then we have to think about what action to take in order to protect ourselves). Both primary and secondary appraisals are very similar to the cognitive functions underlying appreciation of a medical treatment and the probable consequences of one’s treatment options (115).

According to Charland, Damazio's patient is the ideal case of a perfectly competent patient who would pass all mental capacity tests with flying colours. However, should we accept him as a mentally competent individual in the legal and clinical sense of the term? In another example, Charland argues if one should accept the participation of a cancer patient who understands and appreciates what it would mean to enroll in a toxicity test trial and he does so because he hopes he will get better. "If the hope is not entirely misplaced, misinformed, and inappropriate, most of us would probably grant that, in this case, it is a legitimate reason which we can all recognize as a sensible justification. But it is an *emotive* reason." (115) (p. 76) Charland concludes, that "a being without emotions is incapable of effective practical reasoning and decision making...Practical reasoning without cognition is *empty*, without emotion it is *blind*." (115) (p. 78)

In response to Charland's paper, a few authors provided their written support for the incorporation of an emotional component in the evaluation of mental capacity. However, they all recognised that the most difficult aspect of this issue is how to operationalise standards for determining and assessing the contribution of emotion to mental capacity. For example, can we tell whether the absence of emotion is due to the lack of a capacity to experience emotions, or simply due to the lack of strong feelings about the matter at hand? (120-123) In addition, Appelbaum (1999) cautions that in order to justify the expansion of the mental capacity assessment to include emotion, one should be able to show that "there is a substantial target population who would be identified as lacking the capacity for emotion, and who therefore are so profoundly impaired as to be incapable of meaningful choice."(120) (p. 387)

## **Chapter summary**

In this chapter the definitions and standards of assessing mental capacity have been explored within the legal and medical contexts in the UK. More specifically, the first part of this chapter was devoted on the global, domain and decision-making definitions of capacity. This was followed by a detailed description of the legal standards of assessing mental capacity of patients in general medicine and psychiatry. Then, the assessment of the capacity to draft and revoke psychiatric advance statements was considered which was followed by a discussion of the clinical aspects of mental capacity assessment. The final part of this chapter was focused on the emotional components of capacity and the need for expanding the cognitive criteria of mental capacity assessment. In the next chapter, the concept of self-efficacy and its relation to this study will be explored.

## CHAPTER 3

### SELF-EFFICACY

*“A resilient sense of efficacy enhances sociocognitive functioning in the relevant domains in many ways. People who have strong beliefs in their capabilities approach difficult tasks as challenges to be mastered rather than as threats to be avoided. Such an affirmative orientation fosters interest and engrossing involvement in activities. They set themselves challenging goals and maintain strong commitment to them. They invest a high level of effort in what they do and heighten their effort in the face of failures or setbacks. They remain task-focused and think strategically in the face of difficulties. They attribute failure to insufficient effort, which supports a success orientation. They quickly recover their sense of efficacy after failures or setbacks. They approach potential stressors or threats with the confidence that they can exercise some control over them. Such an efficacious outlook enhances performance accomplishments, reduces stress, and lowers vulnerability to depression.” (124)(p. 39)*

According to Bandura (1997) the godfather of this psychological construct, self-efficacy is not a general trait that some individuals possess and others don't but is a set of differentiated self-beliefs linked to different areas of functioning. These sets of beliefs are specific for each activity domain and are not concerned with just the exercise of control over action but also with the self-regulation of thought processes, motivation, affective and physiological states. In other words, perceived self-efficacy is not concerned with the number of skills one has but with what one believes can do with these skills under a variety of circumstances (124). Efficacy beliefs can vary on several dimensions that have important performance implications (e.g. level, generality and strength). First, they vary in terms of the level of task demands that represents different degrees of challenge within a particular domain of activity. For example, one can measure a person's perceived self-efficacy to stick to a health-promoting exercise programme by asking the person to describe the things that make it hard for them to exercise regularly (e.g. when they are under work pressure, are tired, when they have other interesting things to do). Second, efficacy beliefs may differ in terms of generality. “People may judge themselves efficacious across a wide range of activities or only in certain domains of functioning. Generality can vary on a number of different dimensions, including the degree of similarity of activities, the modalities in which capabilities are expressed (behavioural, cognitive, affective), qualitative features of situations, and the characteristics of the persons toward whom the behaviour is

directed. ....Within the network of efficacy beliefs, some are of greater import than others. The most fundamental self-beliefs are those around which people structure their lives.” (124) (p. 43) Third, self-efficacy beliefs differ in terms of strength. Strong self-efficacy beliefs will persist and produce outcomes under adverse circumstances while weak ones will be easily cancelled (124).

Moving on from the main characteristics of self-efficacy beliefs to their role in the process of human adaptation and change, Bandura (1997) has identified five different ways in which self-efficacy contributes to this process (124). First, different classes of activities are governed by similar sub-skills. For example, an executive who runs an advertising company successfully could also run a fund-raising campaign successfully because his sense of being self-efficacious that stems from one domain of activity can be transferred to another by using similar skills. Second, human beings can acquire competencies in different domains simultaneously which can enhance their self-efficacy in learning new things in life. For example, school children are exposed simultaneously to a number of different skills for learning maths, languages, arts, etc. Children who master most of these skills successfully, develop metastrategies which although learnt in one domain of activity can be used in other activity domains. Consequently, their beliefs in their learning capabilities affect how they approach new challenges. Third, self-efficacy beliefs in coping with one type of activity can be generalised in different settings. In a number of different experiments, Bandura was able to show that women who received training on how to disable men in case they attacked them physically or sexually, were able to transfer these skills in different settings, different individuals and different activities. Similar results were obtained when phobics were taught generalisable coping skills. Their increased self-efficacy and coping behaviour was extended beyond the particular threat for which those skills were developed (124). Fourth, by creating cognitive commonalities across diverse domains of activities, people can transfer their self-efficacious beliefs in order to bring about change. Taylor et al (1985) showed that men with uncomplicated acute myocardial infarction who led impoverished lives because they believed they had a permanently impaired heart, were able to increase their self-efficacy in their cardiac capabilities by mastering heavy workloads on a treadmill (125). They believed that the strain their heart was able to withstand on the treadmill exceeded

any physical and emotional strains they were likely to come across in their everyday activities. Finally, human adaptation and change can be achieved when individuals are able to generalize their belief that they can mobilize whatever effort to succeed in different activities. Bandura (1997) outlines a number of experiments where individuals with different phobias (e.g. snake phobia) were able to show metacognitive changes in their perceptions to bring about change in different areas of functioning. One of his patient's reported the following: "The feeling of accomplishment I was experiencing at having overcome the fear of snakes gave me the confidence to overcome my fear of public speaking. I am generally somewhat less timid than I was before. The biggest benefit to me of the successfulness of the treatment was the feeling that if I could lick snakes, I could lick anything. It gave me the confidence to tackle, also successfully, some personal stuff." (124) (p. 53)

So far, a general description of the psychological construct of self-efficacy has been attempted and how it affects human adaptation. Psychological experiments in the 70s and 80s showed that changes in efficacy beliefs regulate motivation and action, that acquisition of self-efficacy is possible through direct or mastery experience, indirect or vicarious experience and verbal persuasion or symbolic experience and finally that personal enablement is achieved by equipping people with knowledge, sub-skills and self-affirming experiences in their exercise of personal control (124;126;127). However, a lot of work has been devoted on identifying the mechanisms that affect and mobilize self-efficacy to facilitate the process of adaptation and change. This part is mainly explained by the Social Cognitive Theory.

### **Self-efficacy within Social Cognitive Theory**

According to the Social Cognitive Theory, our actions are the result of a continuous, dynamic and reciprocal interaction of personal, environmental (situational) and behavioural factors (124). Personal factors include our attitudes, perceptions, values, goals, knowledge and all previous experience. Environmental factors involve all those influences that may both reward or hinder actions and the

achievement of goals. Behaviour is itself an interacting determinant in the process. The relative influence applied by each of the three sets of factors will vary for different activities, different individuals and different circumstances. Kaufman, Mann & Jennett (2005) draw a picture of the interplay of these factors using the following illustration: “In a medical education example, when students are thrust into the busy environment of a clinical ward, they will do what is required to ‘get the job done’ and to meet expectations. In other cases, the behaviour and its feedback will be a major influence (128). For instance, when students are learning and practicing a new skill, the feedback from this will have a strong influence. Finally, in those instances where situational influences are relatively weak, personal factors will exert the strongest regulatory influence. To complete our example, when not pressed by powerful environmental forces, students may choose to learn a new skill, or to learn more about talking with patients. These choices will be affected by the student’s own values, perceived needs and individual goals. There may also be interaction within each factor, as different personal factors, or environmental factors, may influence each other interactively.” (128) (p. 9)

Within Social Cognitive Theory, Bandura identified self-efficacy as a central type of belief that determines individuals’ confidence in performing actions. To study self-efficacy, he looked specifically at behaviour. According to him behaviour is determined by expectations (the consequences of behaviour as they are perceived by the individual) and incentives (subjective evaluations of the importance of a particular outcome or object) (124). There are three forms of expectations:

1. Situation-specific that occur without personal action.
2. Outcome expectations which are the assumed normal consequences of an action.
3. Self-efficacy expectations that refer to our perceived confidence in organising and performing a specific action.

### **Self-efficacy and outcome expectations**

According to Bandura (1997) self-efficacy affects the intention to change behaviour (e.g. quit smoking), the effort invested to reach this goal, and the



persistence to continue striving in spite of barriers and setbacks that may undermine motivation. Research has shown that outcome expectations are seen as particularly important in intention formation but less so in action control while self-efficacy has been shown to be important in both stages (124). Furthermore, it has been shown that self-efficacy is a good predictor of diverse forms of behaviour whereas outcome expectations are predictive if specified and assessed in relation to the actions that can produce them (124;129). To illustrate the relationship between self-efficacy and outcome expectations it is necessary first, to look at three major forms outcome expectations can take and then look at their interactions with self-efficacy beliefs. Outcome expectations can take three major forms:

- The positive and negative physical effects that accompany behaviour (e.g. alcohol can produce physical pleasure, reduce stress, etc. but it can also produce serious health problems).
- The positive and negative social effects such as approval, social recognition and delivery of status and power or disapproval, social rejection and deprivation of privileges.
- The positive and negative self-evaluative effects such as self-satisfaction, a sense of pride and self-worth or self-dissatisfaction, self-devaluation and self-censure.

The following table outlines the different patterns of interaction between self-efficacy beliefs and outcome expectations.

	Outcome expectations -	+
Efficacy beliefs +	Protest Grievance Social activism Milieu change	Productive engagement Aspiration Personal satisfaction
-	Resignation Apathy	Self-devaluation Despondency

**Figure 2: Efficacy beliefs and outcome expectations**

The effects of different patterns of efficacy beliefs and performance outcome expectations on behaviour and affective states. The pluses and minuses represent positive and negative qualities of efficacy beliefs and outcome expectations (From Bandura p. 20).

For example, highly efficacious individuals do not give up trying when their personal actions do not produce desirable outcomes but keep fighting until they achieve change through alterations of unfair social practices. The feminist and gay movements are just a couple of examples that illustrate the relationship between high self-efficacy and low outcome expectations. In contrast, people with low perceived self-efficacy quickly give-up when their efforts yield no results (e.g. people with chronic mental health problems usually report powerlessness). Finally, when people have a low sense of personal efficacy but see others like them enjoying the benefits of successful effort they develop feelings of self-devaluation and despondency (124). “In studies instilling different beliefs about personal efficacy and the success of others, belief in one’s own inability to secure valued outcomes readily attainable by others of similar standing is most conducive to depressive mood and cognitive debilitation of performance”.(124) (p. 21)

The strength of a theory lies in its ability to operationalise and measure its different components. To measure self-efficacy, we can use a variety of scales that take into account the level or magnitude of one’s estimate of one’s best possible performance (e.g. the various degrees of challenge to successful performance), the strength of one’s self-efficacy beliefs (e.g. can one perform the specified activity?) and the generality of efficacy beliefs. Generality refers to whether one can judge

him/herself as efficacious across a wide range of activities or only in certain areas of functioning. Most studies today focus on the measurement of the strength of self-efficacy because this has been shown to be the most predictive aspect (129). Self-efficacy has become a widely applied theoretical construct in models of addiction and relapse, academic and occupational performance, weight management, stress management, pain management, phobic behaviour, adoption and maintenance of various health behaviours and premature attrition from counselling (125-131).

In summary, the social cognitive theory suggests that self-efficacious people are equipped with a dynamic, multifaceted belief system that operates selectively across different activity areas and under different situational demands and provides them with the commitment to engage in an intended behaviour even if failure builds up. But how can one distinguish self-efficacy from other similar psychological constructs? The following section will explore that area.

## **Related views to self-efficacy**

Four psychological constructs are usually confused with self-efficacy:

- Locus of control
- Self-concept
- Self-esteem
- Effectance motivation.

### ***Locus of control***

Self-efficacy beliefs refer to whether one can produce certain actions while locus of control beliefs refer to whether actions affect outcomes. Rotter's locus of control construct, is mainly concerned with people's perceptions about whether their actions are determined by internal (psychological) or external (fate, God) forces (132). As Bandura explains, people who have a strong internal locus of control but who lack the required skills to perform a particular action, will experience a low sense of self-efficacy and will view the activity at hand as futile (124).

### ***Self-concept***

In psychological textbooks self-concept is defined as "the sum of one's beliefs and attitudes toward oneself (133)." It is measured by asking people to rate how well descriptive statements of different qualities apply to themselves (e.g. "I am a kind person" or "I am an active citizen"). Consequently, a score on self-concept will give a researcher an idea about people's self-appraisal and their general outlook on life but it can not predict human behaviour accurately (133). In contrast, self-efficacy beliefs vary across different domains of activities, within the same activity domain at different levels of difficulty and under different circumstances, thus giving greater power to predict human behaviour (124).

### ***Self-esteem***

Self-esteem is another psychological concept that refers to our individual self-appraisal and self-worth (global measure). It is different from self-efficacy that focuses on our perceived capabilities (domain specific). Although both concepts are multidimensional (one can derive a sense of self-worth from his/her family, work, hobbies, etc), they are not simply different aspects of the same phenomenon

(124). For example, an individual with high self-esteem may perceive himself as a clumsy footballer without the latter affecting his self-esteem in any way simply because his self-worth does not depend on that activity.

### ***Effectance motivation***

Effectance motivation refers to “our intrinsic need to deal effectively with the environment.” (124) (p. 13) We develop this motive through accumulation of knowledge and skills in managing and coping with our environment which is similar to the way we develop efficacy beliefs. However, the main difference between the two concepts is again the global nature of effectance motivation that is based on dispositional determinants (a theoretical position that poses difficulties in explaining the variability of human behaviour based on a single intrinsic drive) and the specificity of efficacy beliefs that are defined and measured independently of performance and provide a basis for predicting the occurrence, generality and persistence of behaviour (124).

### **Self-efficacy and mental illness**

The previous section was devoted to the mechanism of self-efficacy which underlies our ability to be self-determining, to plan for the future and see our plans achieved.

To date there is very little research regarding the self-efficacy beliefs of psychiatric patients. The few studies that are found concentrate on the exercise of control on psychiatric symptoms and the acquisition of coping strategies (e.g. training of social cognitive skills, conversational skills, independent living skills, problem solving skills, vocational rehabilitation skills and recreational/leisure skills) through role playing by the users of psychiatric services and modelling, prompting, feedback and reinforcement by the therapist (134-137). Unfortunately these studies have not measured variations in patients' self-efficacy. Liberman et al's (1986) review suggests that (136):

- Users of psychiatric services can be helped to acquire behaviours that will improve their social skills in specific interpersonal situations.

- Users of psychiatric services show moderate to substantial generalisation of trained behaviours to untrained scenes and items for simple behaviours such as eye contact (although generalisation appears to be problematic for complex behaviours such as behaviour change).
- Comprehensive, intensive social skills training can reduce clinical symptoms and relapse in psychiatric patients. Bellack et al's study (1984) showed that people with schizophrenia who participated in a day hospital programme and received social skills training showed symptom reductions that were more durable over a six month follow-up period than those who only received the day hospital programme (137).
- Social skills training alleviates depression for unmedicated depressed outpatients, has clinical effects equivalent to those of antidepressant medication and is associated with a lower rate of drop out from treatment.

Inspired by Liberman's (1986) and Bellack's (1984) works, Barbara McDermott attempted to develop a scale to measure the self-efficacy of patients with schizophrenic spectrum disorders to cope with their symptoms (135). Her study resulted in a scale with two subscales, one that measures positive symptom self-efficacy and one that measures negative/social interaction self-efficacy. The author explains that validating the positive symptom self-efficacy scale was difficult probably because patients who were confident in their ability to control hearing voices did not feel able to get rid of their voices. They just felt their voices were less likely to interfere with other aspects of their functioning. She also found that lack of congruence between positive symptom self-efficacy and positive symptoms translated into generalised feelings of self-efficacy rather than confidence in management of the individual symptoms per se. Another difficulty in validating this sub-scale was the patients' belief that if they complied with their medications they would be able to control their positive symptoms. This resulted in high self-efficacious patients who were still experiencing a significant number of positive symptoms but not necessarily coping very efficiently with them. McDermott suggests that the positive symptom self-efficacy subscale could be used as a general measure of self-efficacy rather than symptom specific while the negative/social interaction subscale could be used as a symptom specific measure.

Her study showed that the presence of negative symptoms led to lower self-efficacy. She suggests that the opposite might be true too but that was not addressed by her study. The small sample size (n=127 at baseline and n=60 at two weeks follow up) and the two-week gap between test-re-test reliability further limit the validity and reliability of the scale (135). Unfortunately, her work has not been taken up by other researchers. Further work in this area is needed in order to shade more light in understanding the causal relationships between self-efficacy beliefs and management and coping with positive and negative symptoms in schizophrenia.

### ***Self-efficacy and empowerment of users of psychiatric services***

Another attempt to study the self-efficacy of patients with psychiatric disorders is found in research around patients' empowerment. Rappaport an advocate of user empowerment in America during the 80s, maintained that empowerment includes the individual's psychological sense of personal control and determination over his/her own life and his/her democratic participation in the life of one's community (138). Following Rappaport's writings and public campaigns for increasing users' empowerment, researchers such as Rogers et al (1997) and Wowra & McCarter (1999) set out to develop and validate the first scale on measuring this construct (139;140). Rogers et al's study produced a valid and reliable instrument comprised of 28 items clustered under five major factors (139):

- self-esteem and self-efficacy
- power-powerlessness
- community activism and autonomy
- optimism and control over the future
- righteous anger (e.g. getting angry about something is often the first step toward changing it, getting angry about something never helps).

According to the authors, "the self-esteem - self-efficacy factor was one of the strongest and most consistent produced by the factor analysis." (139) (p. 1045) The authors also report a number of predictors that increase empowerment such as the number of community activities users engage in, the number of hours worked,

monthly income and quality of life. Their results suggest, “that an empowered person is one who has a sense of self-worth, self-efficacy, and power. The empowered person recognizes use of anger as a motivating force to instigate social change and is optimistic about the ability to exert control over his or her life. He or she recognizes the importance of the group or community to effect change, but the empowered person also values autonomy.” (139) (p. 1046) The validity and reliability of the scale was further explored and confirmed by a big survey on a sample of 2,000 outpatient mental health patients carried out by (140) (1999) .

In summary, the above studies suggest that the Empowerment Scale is a valid and reliable measure and that empowerment can be used in research as a process and outcome measure. In addition, the studies suggest that services aimed at increasing users’ empowerment should focus on increasing users’ self-efficacy and self-esteem, decrease feelings of powerlessness and increasing feelings of power especially by increasing financial resources and community activism.

### **Self-efficacy and its role in advance care planning**

According to Pearlman et al (1995), advance care planning is a process very similar to other health promotion activities such as smoking cessation (141). Pearlman et al (1995) believe that the low uptake of advance statement drafting and the unsuccessful implementation of such documents in the United States, are due to the underestimation of the psychological processes that underlie advance care planning. Focusing on three psychological models used in other health promotion activities, they provide a model that could be used within the advance care planning context (see picture 1). The three models used in this blueprint are:

- The stages of change model (142)
- The health belief model (143)
- The social cognitive theory (124;144)



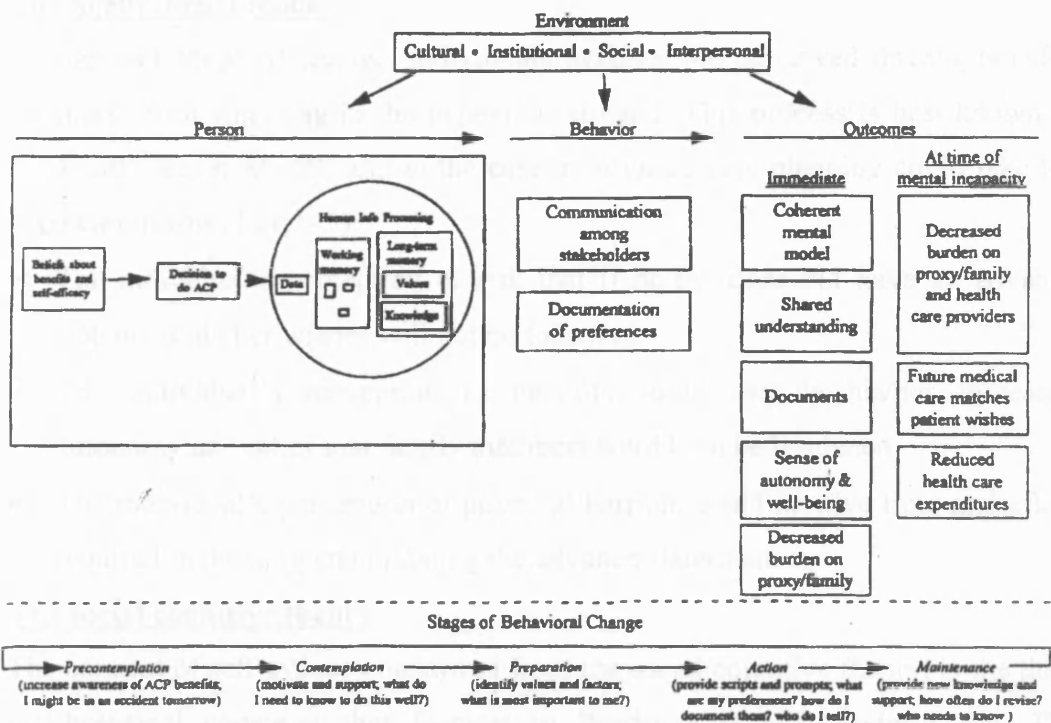


Figure 3: Conceptual model for advance care planning adopted by Pearlman et al (1995)

### The stages of change model

The stages of change model outlines five basic stages in the process of changing a behaviour: precontemplation, contemplation, action, maintenance, and relapse (142). In each of these stages, individual attitudes, intentions and/or behaviours play an important role in the process of change. Pearlman et al (1995) suggest that in the precontemplation stage, individuals may be unaware of the need for advance care planning and unwilling or discouraged about completing advance statements (141). During the contemplation stage people become aware of advance care planning and start thinking about completing an advance statement, gather information and talk about treatment preferences or completion of advance statements. During the action stage, actual completion of an advance statement takes place and communication of the treatment preferences to health care providers occurs. Finally, during the maintenance stage, advance care planning discussions and updating of the advance statements occurs.

### **The health belief model**

Within each stage of change, individuals evaluate the perceived threats, benefits and barriers in engaging in the behaviour at hand. This process is best known as the Health Belief Model, and in the case of advance care planning could take the following forms (141;143):

- The individual's perception of risk that if he/she does not have an advance statement his/her wishes will not be followed.
- The individual's perception of benefits could include his/her increased autonomy and relief that family members would not be burdened.
- The individual's perception of potential barriers could involve time and effort required in drafting and updating the advance statement.

### **The social cognitive theory**

The concept of self-efficacy borrowed from the social cognitive theory, is the third psychological construct that features in Pearlman et al's model (141). The individual's belief in their confidence (efficacy expectation) to taking some action (e.g. thinking about advance care planning and completing an advance statement) and the belief that taking such action (outcome expectations) will have any meaningful effect (e.g. the impact of the advance statement on future care) should be considered and incorporated in the promotion of advance care planning from the outset.

### **Integration and operationalisation of the three psychological models in advance care planning**

To operationalise the above, Pearlman et al (1995) suggest that health providers should prepare a structured interview with questions which will incorporate all of the three models and a patient-centred workbook which will provide people with another opportunity to understand the purpose and relevant issues of advance care planning (141). Examples of structured interview questions could include:

- Exploring the stage of change: "If you became seriously ill today with a life-threatening problem, what should be the goals of your medical treatment? To get better or to make you comfortable?"
- Exploring attitudes to perceived benefits/risks: "What are the factors that influence your choice? Hope for improvement, fighting for life?"

- Exploring self-efficacy expectations: “How confident do you feel drafting an advance statement about a life-threatening problem? If you were in the final stages of an incurable disease and dying, would you still want these treatments, and if so, why?”

A patient-centred workbook could incorporate personal values into the formation of informed and well-considered preferences, knowledge about treatments and health states and questions about areas of uncertainty for discussions with the health providers.

So far there is no available data on the use of Pearlman et al’s model in promoting advance care planning.

### ***Self-efficacy and the preference for care study***

Self-efficacy is defined as confidence in our abilities to execute certain actions. If users of psychiatric services can benefit from social cognitive skills training, then systematic implementation of an educational programme about advance statements that incorporates Pearlman et al’s model could possibly make them more effective in their abilities to design, execute and revoke psychiatric advance statements (141).

I joined the preference for care study a year and a half after the study began because the previous researcher had difficulties recruiting sectioned patients. Because recruitment was well under way it was not possible to introduce a baseline measure that could look at the self-efficacy beliefs of sectioned patients in relation to drafting and implementing psychiatric advance statements. My academic interest in the psychological construct of self-efficacy led me to investigate existing research on self-efficacy that could be introduced at the follow-up phase of the study. My investigation was successful and identified two longitudinal studies on smoking cessation in the Netherlands which showed that an increase in post-treatment level of self-efficacy and an increase of self-efficacy during treatment, were predictors for success and failure after 1 year (130). In the first study (which was part of a research programme about the prevention of smoking in youth), the attitude, social norm and self-efficacy scores of the control group at the first measurement (T1) were used to predict intention and behaviour at

a following measurement one year later (T2). Analysis of the results showed that self-efficacy at T1 was the best predictor of smoking intention at T2 explaining 24% of the variance. Self-efficacy at T1 also had a unique contribution in the prediction of behaviour at T2 when added after the intention T1 (130). In the second study, researchers used two self-efficacy questionnaires to evaluate success of a three-week 'stop smoking' programme (130). At the pre-treatment self-efficacy measure, respondents were told to imagine that they were quitting without professional assistance, to minimise the effect of programme-efficacy expectations. Success rates of the programme were 54% after treatment, 44% after 6-weeks follow-up and 27% after 1-year follow-up and were comparable to rates of other studies. There were no differences between the groups of quitters and smokers after one year with respect to any measure on the pre-test. Researchers divided the participants that were successful after the treatment in three success/failure groups:

- A: post-treatment success, post-6-weeks success, post-1-year success.
- B: post-treatment success, post-6-weeks success, post-1-year failure.
- C: post-treatment success, post-6-weeks failure, post-1-year failure.

The researchers predicted the membership of the three groups from the self-efficacy scores at the post-treatment measure and the increase in self-efficacy during treatment (130). Post-treatment self-efficacy predicted success and failure after one year (129;130;145).

Garcia et al (1990) further explored the hypothesis whether self-efficacy predicts future behaviour better than does past behaviour (146). They studied smokers who were trying to quit on their own. They also tried to answer whether success or failure in coping with particular high-risk situations affect efficacy evaluations and whether different coping mechanisms were associated with different levels of self-efficacy. Their findings showed that baseline efficacy ratings were weak predictors of success. Their explanation for this result suggested that people learn from their initial experience and develop more realistic efficacy evaluations as they go. Their results also suggested that previous smoking rate predicted future smoking rate as well as self-efficacy ratings. Moreover, their findings showed that successful coping led to an increase of personal efficacy while failure led to a decrease. The

type of coping (e.g. cognitive, behavioural, no coping action) also affected efficacy ratings. For example, in situations where participants smoked, efficacy ratings were lower when no coping action was taken than when behavioural or cognitive coping techniques were used (146).

It is worthwhile noting that all of the above studies used specific (e.g. the pre-abstinence efficacy scale or ratings of participants' confidence in abstaining in a particular risky situation on a ten point scale) self-efficacy questionnaires.

Following the above mentioned research, a self-efficacy questionnaire was introduced at the follow-up phase of the study. The questionnaire aimed to look at self-reported generalised (e.g. "I am confident that I could deal efficiently with unexpected events") and specific (e.g. "I can manage my own mental health", "I can make decisions about my future care") self-efficacy beliefs of sectioned patients (147) (see appendix 11).

## **Chapter summary**

To summarise, in this chapter I defined the concept of self-efficacy within the context of social cognitive theory, I gave a brief explanation of its relation to other related concepts such as self-esteem, I summarised the few studies of the evaluation of self-efficacy in people with mental health problems and I explained the rationale for the use of the self-efficacy scale at the follow-up stage in this study. In the next chapter the literature on randomised controlled trials will be explored.

## **CHAPTER 4**

# **RANDOMISED CONTROLLED TRIALS**

### **Introduction**

Scientific research methods involve the systematic observation of the phenomenon of interest. Systematic study of phenomena requires the existence of rules and processes that investigators follow thoroughly and against which the research can be evaluated (148). Randomised controlled trials are regarded as the “gold standard” of outcome research because randomisation ensures that all forms of bias are controlled for in an experiment to test the effects of an intervention. Outcomes (also known as dependent variables) are events that are present or absent after the participants receive the interventions. In clinical practice the main characteristics of randomised controlled trials involve two or more groups of individuals (called the participants) who are randomly allocated into experimental and control groups. The participants of the two groups should be drawn from the same population and ideally should be identical in all respects except that those in the experimental group will receive one or more clinical interventions (also called the independent variable(s)). The two groups are studied systematically under similar, known, tightly defined and controlled conditions in order to avoid variation between them. The strength of the outcome of a randomised controlled trial is mainly due to the accurate assessment of the effects of the intervention. This is mainly achieved by the random allocation of participants that balances the effects of any extraneous, confounding variables (e.g. selection biases) and increases scientific confidence in the effect of the intervention. Randomised controlled trials are considered the only scientific designs that can determine cause and effect relationships. Another characteristic of randomised controlled trials is the pre-and post-testing condition. The experimental and control groups receive a number of measurements (e.g. questionnaires, interviews, clinical assessments) before and after the intervention. Apart from strengthening confidence in any observed differences (or lack of them) between the two groups, the pre-and-post

testing condition offers explanations for the direction of any associations between the independent and dependent variables.

In the following paragraphs the strengths and weaknesses of randomised controlled trials will be explored and reasons discussed for the use of this type of experimental design in the present study.

## **Randomised controlled trials in health care evaluation**

Randomised experiments may be the preferred method for studying cause and effect relationships but in health care settings the design and implementation of randomised controlled trials may be inappropriate, unnecessary or impossible to carry out. Bowling (1997), Jadad (1998) and Britton et al (1998) outline some of the reasons for the inappropriateness of randomised controlled trials in some settings (148-150):

- Financial, legal and ethical constraints may prevent the execution of randomised controlled trials for the study of infrequent and adverse effects of medical treatment.
- Questions related to the aetiology and natural history of diseases should not be influenced by investigators.
- Randomised controlled trials are not the best method of evaluation of long-term outcomes of medical treatments (e.g. 10-20 years ahead) because researchers cannot keep people in controlled arms for so long.
- Random allocation of participants may not always produce the best effect of an intervention (e.g. when participants have very strong preferences for or against the intervention).
- Randomised controlled trials may not always produce generalisable results because of the involvement of highly selected centres (e.g. teaching hospitals), participants and investigators.

To overcome these barriers and a number of biases inherent in randomised controlled trials (experimenter biases, demand characteristics, sample attrition) investigators have come up with different types of randomised controlled trials suitable for a variety of populations, settings and interventions. Jadad (1998) has summarised the different types of RCTs in the following table (150):



<p>RCTs according to the aspects of the interventions they evaluate:</p> <ul style="list-style-type: none"> <li>• Explanatory and pragmatic trials</li> <li>• Efficacy and effectiveness trials</li> <li>• Phase I, II and III trials</li> </ul>
<p>RCTs according to how the participants are exposed to the interventions:</p> <ul style="list-style-type: none"> <li>• Parallel trials</li> <li>• Crossover trials</li> <li>• Trials with factorial design</li> </ul>
<p>RCTs according to the number of participants:</p> <ul style="list-style-type: none"> <li>• From n-of-1 to mega-trials</li> <li>• Fixed size</li> <li>• Sequential trials</li> </ul>
<p>RCTs according to whether the investigators and participants know which intervention is being assessed:</p> <ul style="list-style-type: none"> <li>• Open trials</li> <li>• Single blind trials</li> <li>• Double blind trials</li> <li>• Triple and quadruple-blind trials</li> </ul>
<p>RCTs according to whether the preference of non-randomised individuals and participants are taken into account:</p> <ul style="list-style-type: none"> <li>• Zelen's design</li> <li>• Comprehensive cohort design</li> <li>• Wennberg's design</li> </ul>

**Table 8: Different types of RCTs.** Adopted by Jadad p. 11

## **Internal Validity**

### ***Effects of attrition***

The randomisation process eliminates the possibility of systematic allocation bias or risk of confounding which is the major criticism of non-randomised controlled trials. However, one of the common threats to internal validity of randomised controlled trials, “is the introduction of bias through non-random losses of participants at different stages of the study....If subjects who are likely to drop out at different stages of the study can be excluded from randomisation, internal validity will be improved but this has to be weighed against potential loss of generalisability (149) (p.23).” One of the common strategies employed to deal with attrition of participants during the different phases of the study is the intention to treat analysis where the lost randomised participants are treated as if they had completed the study.

### ***Patient preference***

Possible interaction effects can threaten the internal validity of a randomised controlled trial. Interaction effects are the result of the association of extraneous factors with the dependent variable that cause variation in it when the independent variable is under investigation. So individual preferences for or against an intervention can increase or decrease its effect. Interaction effects are particularly difficult to identify because of the large number of patients required to be recruited. For example in order to detect a 10% increase in survival, 1,000 patients would be needed at 90% power and the 5% level of significance. In order to identify an interaction effect of 10% between preferences and treatments we would need several thousand for the same power (148). However, it is very important to be able to separate the treatment effects from individual preferences. Lack of empirical evidence about how individual preferences work (some studies suggest they may work similarly to placebos) restrict conclusions to observations that preferences do exist and that special study designs such as those described above are necessary (149;151).

### ***Reactive effects***

Ann Bowling (1997) uses the term ***reactive effects*** to describe any changes in the participants' attitudes, behaviours and feelings by simply taking place in a study (148). The Hawthorne effect (participants change because they are treated differently), evaluation apprehension (participants exhibit increased levels of anxiety because they are being tested), demand characteristics (participants guess the hypothesis and behave in a way that will please the experimenter) and experimenter bias (unconscious communication of the experimenter's desires to the participants) may all undermine the study's validity. The best way to avoid these types of biases is to apply multiple levels of blinding.

## **External validity**

As mentioned above, the aim of conducting randomised controlled trials in health care settings is to measure the effect of an intervention and to provide an informed basis for future clinical decision-making. When it is possible to generalise the results of a randomised controlled trial to a wider health care setting and patient population then the study has external validity. To safeguard external validity researchers have to define clearly the patients involved in the study, the clinicians and the treatment providers.

### ***Participation or selection biases***

Participation biases may pose a threat to the external validity of a randomised controlled trial if the centres recruited in the study are specialised units of health care or teaching hospitals. Although there is no direct evidence for this suggestion (149;152), it is believed that non-randomised controlled trials are more likely to include a broader range of health care facilities and more typical clinical practice.

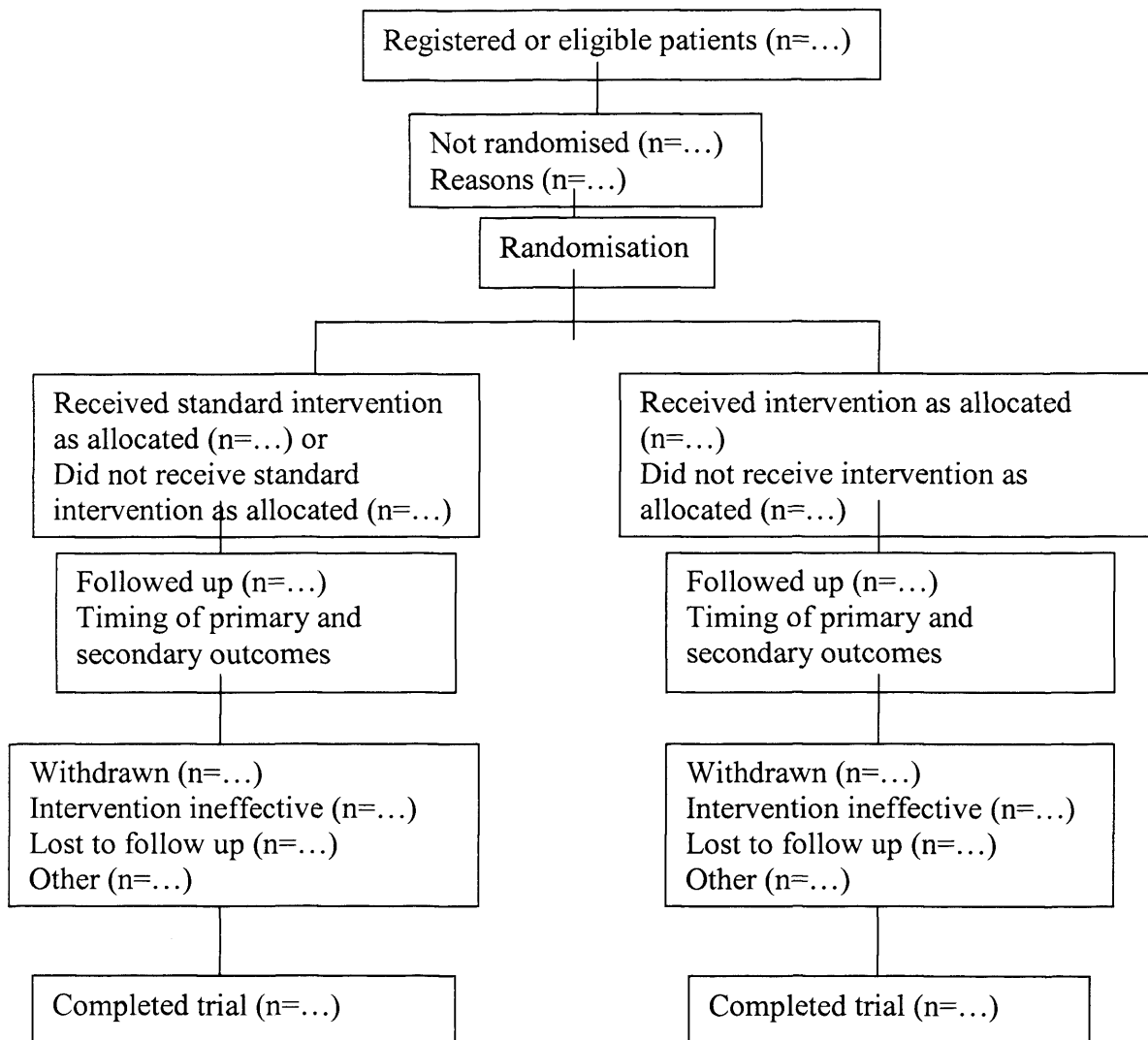
Clinician preferences may further reduce the generalisability of results by not inviting eligible patients to participate in the study (149;150).

Participation bias can also be introduced whenever there are great differences between the characteristics of participants and non-participants. Eligible patients may refuse to participate in a trial because they have a different preference or because they don't like getting involved in any research. Britton et al (1998) performed a systematic analysis of 16 randomised controlled trials and identified different types of participation bias in treatment and prevention studies. In treatment studies the participants were usually male, younger than average, non-white, less educated, of lower socio-economic status, smokers, had inadequate social support and had no private insurance. In terms of their clinical characteristics, they had more severe or advanced disease, more comorbidity, poorer health status or quality of life. In prevention trials the picture was quite different. Participants were more likely to be younger, of higher socio-economic status in terms of income, housing, education or car ownership and they believed in or adopted a healthy lifestyle (e.g. non-smokers and those who take regular exercise). Such differences between participants and non-participants in

randomised controlled studies, apart from undermining the effect of the intervention and the generalisability of results, could also have important ethical implications. For example, were the less educated and more severely ill in treatment trials able to give full informed consent?

## **The CONSORT statement**

Reporting the characteristics of service providers, participants and non-participants in randomised controlled trials has become a standard followed by most journals today. This initiative took place in 1996 when two groups (the Standards of Reporting Trials group –SORT and the Asilomar Working group on Recommendations for Reporting of Clinical Trials in the Biomedical Literature) of clinical epidemiologists, bio-statisticians and journal editors produced the *Consort statement* (Consolidation of Standards for Reporting Trials)(153). The consort statement contains a checklist of 21 items and a flow diagram, which aim to improve the documentation of randomised controlled trials and make interpretation of their results clearer (150;154). The consort statement is a guide to the various stages of a study including the numbers of eligible participants, the numbers of participants not randomised and reasons for exclusions, the numbers of randomised ones, the drop out and the follow up rates (see Figure 1 reproduced from Begg et al, 1996). The two groups decided on these items because there is empirical evidence that if they are not reported, biases will result in the estimates of the effects of interventions (153). “Like other studies, randomised trials are open to bias if done badly. It is thus essential that randomised trials are done well and reported adequately. Readers should not have to infer what was probably done, they should be told explicitly.... It seems reasonable to hope that, in addition to improved reporting, the wide adoption of this new publication standard will improve the conduct of future research by increasing awareness of the requirements for a good trial.” (154) (pp. 570-1)



**Figure 4: The CONSORT diagram**

Flow chart describing progress of patients through randomised trial (Reproduced from Begg et al. 1996)

But has the CONSORT statement fulfilled its aim? Moher et al (2001) investigated whether use of the CONSORT statement is associated with improvement in the quality of reports of randomised controlled trials (155). They carried out a comparative before-and-after evaluation in which reports of randomised controlled trials published in 1994 (pre-CONSORT) were compared with randomised

controlled trials' reports from the same journals published in 1998 (post-CONSORT). They included 211 reports from *BMJ*, *JAMA*, and *The Lancet* (journals that adopted CONSORT) as well as *The New England Journal of Medicine* (a journal that did not adopt CONSORT and was used as a comparator). Their main outcome measures included the number of CONSORT items incorporated in a report, frequency of unclear reporting of allocation concealment, and overall trial quality score based on the Jadad scale, a 5-point quality assessment instrument. Their results showed that compared with 1994, the number of CONSORT checklist items in reports of randomised controlled trials increased in all 4 journals in 1998, and this increase was statistically significant for the 3 adopter journals (pre-CONSORT, 23.4; mean change, 3.7; 95% confidence interval [CI], 2.1-5.3). The frequency of unclear reporting of allocation concealment decreased for each of the 4 journals, and this change was statistically significant for adopters (pre-CONSORT, 61%; mean change, -22%; 95% CI, -38% to -6%). Three of the 4 journals also showed an improvement in the quality score for reports of randomised controlled trials, and this increase was statistically significant for adopter journals overall (pre-CONSORT, 2.7; mean change, 0.4; 95% CI, 0.1-0.8). The authors concluded that the use of the CONSORT statement was associated with improvements in the quality of reports of randomised controlled trials. Egger et al (2001) reported similar findings in their analogous study (156). However, they also suggested that the original CONSORT statement "lacked clarity and that the information presented in the flow diagram was incomplete. Our results indicate that there were problems with both the original design of the flow diagram and its implementation by authors. For example, most flow diagrams provided the number of individuals randomized, although this count was not explicitly requested. Conversely, only about half of flow diagrams included the number of participants who actually received treatments as allocated, an item included in the original template. The number of participants included in the main analysis was not an item in the recommended flow diagram, and this number was included in only a few diagrams (23.0%). This finding is of concern because the latter count is essential for appraising whether a trial has been analyzed by intention to treat." (156) (p.1999)



## **Exclusions**

To improve the internal validity of a randomised controlled trial researchers exclude patients on medical (e.g. high risk of adverse effect, benefit already established, expected benefit is reduced), ethical (e.g. involving pregnant women in treatments with high risk complications), administrative (e.g. children, elderly, drug users) and scientific grounds (e.g. cancer patients may be excluded from a study for heart disease because they may confuse the picture or decrease the power of the study). The most commonly excluded groups from RCTs are the elderly, people from ethnic minorities and women (149). However, when the eligibility criteria of a randomised controlled trial are defined very narrowly the study may fail to produce any evidence regarding the characteristics of excluded patients and its external validity may be compromised. In addition, clinicians may inappropriately generalise the results to excluded groups or may fail to provide effective treatment to those who need it because their decision making is based on the available evidence (148-150).

## **Are randomised controlled studies superior to non-randomised ones?**

Recent systematic reviews of randomised and non-randomised studies show that although there are large differences in how the research is conducted using the two approaches such as the population included, the setting, the practitioners and how the outcomes are assessed, there is no evidence “to support the argument that a systematic bias arises from the use of one method rather than the other...” (149) (p. 59). Britton, et al (1998) suggest that the results obtained from the two approaches are frequently similar, that any differences they found were usually of similar magnitude of the estimated treatment effect and that very rarely the two approaches favoured different interventions (149). They also showed that differences in results between randomised controlled studies and non-randomised ones were frequently smaller than those between randomised controlled studies or between non-randomised studies.

Ioannidis et al (2001) also agree that there is a high correlation in the estimated efficacy of medical interventions between randomised and non-randomised studies (157). However, their systematic analysis of 45 medical topics also suggested that non-randomised controlled trials show “larger treatment effects” and that between-study heterogeneity was “frequent among randomised trials alone (23%) and very frequent among non-randomised studies alone (41%)”. Finally, they suggest that publication bias and a time lag to publication occur for negative studies regardless of study design.

The most persuasive argument for the superiority of randomised controlled studies over non-randomised ones is that randomisation leads to comparable groups and most importantly, that it determines causal relationships. However, as Abel & Koch (1999) explain “randomisation only implies the equality of the distributions of variables measurable at the time of randomisation (158). It leads to the statistical control of imbalance in the baseline variables and permits probability statements on differences between the groups regarding these variables. It has no influence on everything that happens between randomisation and the assessment of the outcome. Therefore, randomisation itself does not lead to balance in

differences in the quality of treatment and doctors' commitment, differences in patients' motivation, differences in general patient care (e.g. accompanying treatment and ancillary care), differences in the experimental environment and differences in observation (e.g. definition of outcome, measurement of outcome, quality of data collection and follow-up)" (158) (pp.488-9). They also argue that randomisation is neither a necessary nor a sufficient condition for inferring causality. They explain that statistical analysis itself (accepting or rejecting the null hypothesis) does not demonstrate causality and that a number of medical facts from clinical experience can satisfy the condition of causality without the involvement of randomisation. To support their argument they cite medical breakthroughs, like penicillin, aspirin and corticosteroids which were introduced on the basis of historical controls. Finally, they cite a list of procedures that if followed they could lead to very well designed and accurate non-randomised studies. These include the following:

1. Specify a zero time that will be used in determining patient eligibility and adjust for baseline differences in prognostic risk.
2. Determine eligibility according to the same criteria of inclusion and exclusion that would be used in a randomised trial.
3. Classify the patients according to suitable clinical criteria to enable adjustment for any inequalities in susceptibility to the outcome.
4. For the main analysis, use the same statistical strategies (e.g. intention to treat procedures) as those employed in a randomised trial. (158) (p. 492)

## **Recruiting patients with mental health problems into randomised controlled trials**

Recruiting patients with mental health problems into randomised controlled trials is particularly difficult because of the combination of medical, ethical and administrative constraints. The symptoms of mentally ill patients may make it particularly difficult for them to focus on tasks such as long questionnaire completion or to concentrate on extended interviews with researchers. The nature of their condition and the vulnerability associated with it makes the process of obtaining full informed consent time consuming and subject to a number of ethical considerations. Finally, substantial variations in working policy and practice among the different hospitals and community psychiatric teams create obstacles to identifying, approaching and recruiting suitable candidates in different research projects (159).

### **Chapter Summary**

In this chapter, the different types of randomised controlled trials (RCTs) have been briefly outlined and the concepts of internal and external validity in relation to different types of RCTs have been discussed. In addition, the literature associated with the CONSORT statement has been explored as has been the debate about whether RCTs are superior to non-randomised ones. Finally, the difficulties recruiting patients with mental health problems into RCTs were outlined. In the next chapter the aims and hypotheses of the preference for care study will be explored.

## **CHAPTER 5**

### **Rationale, aims, hypotheses**

#### **Chapter overview**

In this chapter, I will introduce the rationale for this study, the research questions the study set out to answer and the hypotheses that were born out of the research questions which were tested.

#### **Rationale for choice of hypotheses**

The choice of sectioned patients as the focus for the trial was based on two premises. The first one was the increase of formal admissions under the Act from 16,000 in 1989 to 27,000 in 1999 (160). The second one was the serious psychosocial implications of sectioned admissions such as infringement of personal liberty and stigma. In addition, the preparation and implementation of a psychiatric advance statement could lead to different pathways of care such as voluntary re-admissions or no admission at all and while preserving users' liberties and self-determination. The Mental Health Act 1983 aims to protect individuals who are at risk of becoming dangerous to themselves or others. Psychiatric advance statements aim to protect patient self-determination and autonomy. These two approaches are not mutually exclusive. A state centred approach and a person centred approach can complement each other. For example, when a sectioned patient is asked to specify his/her own treatment preferences, he/she may feel less coerced and disempowered under the Mental Health Act. When his/her section expires the psychiatric advance statement may stay in effect and prompt compliance with treatment when there is no legal obligation to do so. In addition, Mental Health Act provisions may mobilise emergency psychiatric evaluation and hospital admissions while an existing psychiatric advance statement may cover prior consent for admission and treatment (42;161). Currently, this approach is strongly recommended by the expert committee on the review of the Mental Health Act 1983 and the new Mental Capacity Act 2005 (27;28).

In terms of choosing patient satisfaction as an outcome measure, we did so because recent studies suggested a significant association between patient satisfaction and treatment outcome and patient satisfaction and global reports of outcome (162;163).

This is the first study that measured the self-efficacy beliefs and expectations of sectioned patients. Self-efficacy is an important psychological construct that refers to the individual's confidence in his/her ability to carry out a certain action. Studies on smoking cessation in the Netherlands showed that an increase in post-treatment level of self-efficacy and an increase of self-efficacy during treatment, were predictors for success and failure after 1 year (130). This study looked at whether patients in the intervention group would score higher on generalised self-efficacy beliefs in comparison to the control group.

### **Aims of the study**

The preference for care study is a pragmatic, randomised controlled trial that aimed to evaluate:

- Whether the use of advance statements by sectioned patients who are near discharge from section, leads to lower rates of compulsory readmission to hospital.
- Whether patients who have completed psychiatric advance statements report higher self-efficacy.
- Whether patients who have completed psychiatric advance statements report higher satisfaction with psychiatric services.

### **Hypotheses**

1. Sectioned patients' advance statements for psychiatric treatment, when disseminated in written form to key-workers and general practitioners and

included in patients' case records will reduce the frequency of compulsory re-admissions to hospital.

2. Sectioned patients who have completed advance statements for psychiatric treatment will report higher generalised self-efficacy than patients who have not.
3. Sectioned patients who have completed advance statements for treatment will report higher satisfaction with psychiatric services than patients who have not.

In the next chapter, the setting of the study will be described, the inclusion and exclusion criteria for participation, the materials used, the procedures carried out and the statistical analysis performed.

**PART II**  
**CHAPTER 6**  
**METHOD**



## **Chapter overview**

In this chapter, the setting of the study will be described, the inclusion and exclusion criteria for participation, the materials used, the procedures carried out and the statistical analysis performed.

## **Setting**

Two inner city psychiatric hospitals were used for the recruitment of patients. The Royal Free Hospital in North West of London and St Ann's Hospital in North London. The two hospitals were chosen because of the ethnically diverse populations they serve, the broad spectrum of socio-economic strata they cover and their increased rate of sectioned admissions which is a characteristic of London hospitals (The Statistical Bulletin, Department of Health). During the conception of the study, Royal Free data showed that 200 patients were admitted annually on sections 2, 3 and 4 to the Royal Free and 280 to St Ann's hospital. Fifty percent were readmitted within twelve months, 50% of whom were on a further section of the Mental Health Act.

St Ann's hospital serves a catchment area of almost 250,000 people and has approximately 200 acute adult mental health beds. The Royal Free hospital serves a catchment area of 110,000 people and at the time of recruitment had approximately 60 beds. The patients were recruited from three acute psychiatric wards at the Royal Free Hospital and five acute psychiatric wards at St Ann's hospital.

The study was conceived in 1996 when the formation of community mental health teams and the emphasis on patient empowerment were the main focus of psychiatric services in the UK. In 1991 the Care Programme Approach and the Health of the Nation policies came into effect in order to maximise user and carer involvement (164). However, as was mentioned in chapter one, research suggested that the Care Programme Approach system may be meeting the needs of professionals by ensuring regular client review and clear documentation of the care plan but that patients and carers can feel subject to a degree of coercion in Care

Programme Approach meetings. Psychiatric advance statements are designed to promote patients' empowerment, autonomy and self-determination. Therefore, the opportunity to complete psychiatric advance statements outside the Care Programme Approach meetings would closely involve patients in their care and consequently improve their autonomy. Given the limited time and expertise of the patients' clinicians, it was decided that the psychiatric advance statements would be prepared by the patients with my help and would be placed at the front of their hospital records so that can be easily accessible at any time. We also believed that researchers outside the patient's team would be unbiased and more likely to advocate the patient's rights and preferences. The decision to place the advance statements at the front of the patients' hospital records and to disseminate them to patients' GPs and key-workers was in accordance with the report of the expert committee on the review of the Mental Health Act 1983 and NICE guidelines (28).

1.1.8.2 When advance directives have been agreed, copies should be placed in primary-care and secondary-care case notes/care plans, and copies given to the service user and his or her care coordinator. If appropriate, and subject to agreement with the service user, a copy should be given to his or her carer.
-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

**Table 9: NICE guidelines for schizophrenia :** <http://www.nice.org.uk/pdf/CG>

Placing the psychiatric advance statements at the front of the patients' hospital records and sending one copy to the patients' general practitioner and one to their Care Programme Approach key-worker was thought to be a comprehensive approach to the implementation and evaluation of such instruments which was explicitly explained by NICE guidelines at the time.

## **Participants**

In-patients under sections 2, 3 or 4 of the Mental Health Act 1983 for England and Wales who were due for discharge in the 12 months October 1997 to October 1998 were recruited. Section 2 allows a patient to be compulsorily admitted to hospital for assessment, section 3 for treatment and section 4 for assessment in emergency. The three section categories were considered together because the majority of patients on section 4 are usually transferred to section 2 or 3. Between 1995-1996 when the study was designed, 828 patients were transferred from section 4 to section 2, 303 to section 3 and 432 to informal, in England (160). The choice of sectioned patients as the focus for the trial was based on two premises. The first one was the increase of formal admissions under the Act from 16,000 in 1989 to 27,000 in 1999 (160;165). The second one was the serious psychosocial implications of sectioned admissions such as infringement of personal liberty and stigma. Patients near discharge from hospital were recruited because their ability to manage their mental illness was likely to be improved, their insight was more likely to have been restored and their cognitive abilities related to competence evaluation would be restored, while their experience of their sectioned admission to hospital was still fresh in their minds. It was considered that all these factors would help in the completion of psychiatric advance statements.

Inclusion criteria were age 18 years and over and the ability to read and write English. It was also decided that only patients who were competent would be recruited in the study. The decision to recruit competent adults in the study was based on both legal and pragmatic purposes. Competent individuals of 18 years and over can give informed consent and according to common law can provide oral and written psychiatric advance statements. Sectioned admissions are less common among children and adolescents. The ability to read, write and understand English was essential for many reasons:

- Patients had to give informed consent in order to participate in the study which involved reading and understanding the written summary of the study and the informed consent form (see appendix 2).
- Patients had to read and complete a number of self-report measures (see description of the instruments in the following sections).

- Drafting the advance statement involved understanding of the medical and legal concepts associated with it.
- The funding obtained for the study did not allow for the hiring of translators for those patients who did not read and write English.

Exclusion criteria were kept to a minimum in order to maximise the external validity of the trial (see Table 10). Patients under other specialised sections, those about to be transferred to other sections of the Mental Health Act or to other hospitals and those with organic and psychoactive substance use disorders were excluded for two main reasons:

- to avoid losses to follow-up
- to avoid ethical problems associated with mental incapacity and informed consent characteristics of people with organic and psychoactive substance disorders.

<b>Inclusion</b>	<b>Exclusion</b>
Competent adults Age: 18 years and over	Patients on other sections of the Mental Health Act
Patients on section 2, 3 or 4 of the Mental Health Act	Patients about to be transferred to other sections of the Mental Health Act or to other hospitals
Ability to read and write English	Patients with organic and psychoactive substance use disorders

**Table 10: Inclusion and exclusion criteria**

Individuals who refused, or were unable to give informed consent were not included in the study. For ethical reasons, only data on sex, ethnic origin and type of section were collected on non-participants.

## **Sampling Technique**

Patients were allocated randomly using a block design, stratified according to whether this was the patient's first ever or subsequent section. Blocks of 12 (six experimental, six control) random combinations were prepared and sealed in opaque envelopes. When a patient agreed to participate in the study, an independent colleague in the trial centre was called who chose the next envelope in each case. To be blind to the patient's allocation was impossible as I was required to assist patients to make a directive in those allocated to the intervention group.

## **Outcome measures**

There are many advantages to outcome assessment in mental health services. Outcome assessment may improve quality of care, provide an aid to decision making in clinical practice, evaluate the clinical and cost-effectiveness of interventions in clinical trials and inform government policy formulations (166). However, sceptics are weary of un-interpretable and unwieldy outcome measures that may become a bureaucratic hindrance to successful patient care (167).

Evaluating outcome in mental health care involves complex research processes at both the service level and the patient level (168). As Trauer said “despite major advances in therapies, the links between interventions and changes in health status are often tenuous. The term ‘treatment-resistant’ acknowledges the fact that intensive intervention is sometimes followed by minimal change. Conversely epidemiological studies remind us that not insignificant numbers of persons appear to recover spontaneously (i.e. without intervention) from seemingly serious disorders. Also, what constitutes an intervention? A patient might be in receipt of several medications, supportive therapy and case management. Since we generally can not disentangle the active ingredients of therapy, we can not unequivocally specify the intervention.” (169) (p. 338) However, I believe that use of the experimental method can measure change in psychiatric status and other outcome measures.

The different domains of outcome in psychiatry involve well being (e.g. quality of life), cognition/emotion (e.g. psychopathology, personal constructs), behaviour (e.g. functional status, activities of daily living), physical health (e.g. physical well being), interpersonal (e.g. vocational, educational, residential status and interpersonal relationships), society (e.g. economic, public safety, burden to relatives) and services (e.g. satisfaction with services and treatment, empowerment) (166;168). To obtain data and assess the above domains, researchers resort to either administration based data sources such as public health and medical records or to clinical based sources such as standardised patient self-report and clinical assessment instruments (163;166-168). Administrative based outcome assessments may include mortality, service utilisation (e.g. rate of

admissions-discharges), employment or criminal activity. Clinical based outcome assessments may involve symptom level, social or role functioning, quality of life and satisfaction with services. Neither of the two sources is superior to the other. For example, service utilisation data such as admission and discharge rates is relatively easy to collect from hospital databases on all users of psychiatric services but it is difficult to interpret. According to recent systematic reviews, illness severity is not linearly correlated with service use (163). Service use may depend on many variables other than mortality and morbidity such as patients' socio-demographic characteristics, relationship with professionals and the resources available, national policies and intrinsic characteristics of the service (163). In addition, the existing gaps in clinical based measurements (e.g. the need for further psychometric testing of existing tools with minority groups) leave researchers with no gold standard of outcome measurement.

To assess all outcome domains in psychiatry is impractical. For that reason five main domains were chosen: service utilisation, psychiatric status, satisfaction with services, user and professional views.

### ***Main outcome***

The need to obtain a robust, primary outcome measure for all users, the difficult group of participants (e.g. sectioned patients), the costs of collecting meaningful data over a two year period in two busy inner city psychiatric hospitals, and finally the ethical and legal concerns surrounding the implementation of psychiatric advance statements, led to the choice of ***the rate of compulsory re-admissions*** as the main outcome measure.

As it was discussed above, the rate of compulsory readmission in the year after discharge from section was high. Furthermore, a sectioned admission has a direct impact on personal liberty and choice. The preparation and implementation of a psychiatric advance statement could lead to different pathways of care such as voluntary re-admissions or no admission at all and while preserving users' liberties and self-determination.

### ***Secondary outcomes***

In evaluating the effectiveness of psychiatric advance statements it is also important to see if they can improve users' clinical status and satisfaction with the services they received. For that purpose data was gathered on:

- Time spent in hospital compulsorily or voluntarily.
- Reported symptoms of mental illness.
- Patients' satisfaction with service delivery.
- Patients' perceived self-efficacy.
- Use of anti-psychotic medication.

Although it is difficult to be certain which variable has caused which change in psychiatric research, we hoped that psychiatric advance statements would lead to greater sense of autonomy, better engagement with services, less coercive admissions, and better mental health.



## **Materials**

In order to evaluate the impact of advance statements on the primary outcome and maximise the response rate, I searched the hospital records for data on voluntary and involuntary admissions for the five years before baseline and over the 12 months of follow-up. In order to examine their effect on other secondary measures that are an integral part of the objectives of community psychiatric care, two questionnaires were designed one for baseline and one for follow-up (see appendices 6 and 14). In addition, a number of other standardised measures were used at baseline and follow-up.

### ***Baseline materials***

#### **Demographics**

In 1989, the Department of Health for England, in conjunction with the Office of Population Censuses and Surveys (OPCS) planned and carried out a series of surveys, which aimed to estimate the prevalence of psychiatric morbidity among adults aged 16-64 living in Great Britain (162;170). The survey results showed that:

- psychiatric disorders were commoner in women,
- the peak prevalence of disorders was between 25 and 54 years,
- high risk groups correlated with social disadvantage (e.g. people from ethnic minorities, lone parents and those in single person households such as divorced, separated and widowed)
- prevalence of psychiatric disorder was commoner in lower socio-economic groups,
- high prevalence was strongly associated with unemployment,
- living in urban areas was strongly correlated with psychiatric morbidity.

In terms of the demographics of sectioned patients, the Statistical Bulletin in 1998 showed that out of 10,518 adult sectioned patients in NHS facilities, 6,535 were male and 3,983 female (160). Of those male sectioned patients, 124 suffered from psychopathic disorders, 441 from mental impairment, 116 from severe mental impairment and 514 from non-specified mental illness. Of the female sectioned patients 61 suffered psychopathic disorders, 121 from mental impairment, 26 from

severe mental impairment and 433 from non-specified mental illness. No data were provided on ethnicity and marital status of sectioned patients.

In this study, data were collected from case notes on patients' demographic characteristics. The data were double-checked with the patients and hospital staff in order to identify whether the recruited sample was representative of the general sectioned inpatient population. The data gathered included (see appendix 6):

- Age
- Gender
- Ethnicity according to OPCS (1990)
- Marital status
- Household composition (whether the patient lived alone, with a partner, etc.)
- Employment status
- Diagnosis

### **Psychiatric status**

Two validated and standardised questionnaires, BASIS-32 (171) and HoNOS (172) were used to assess the patients' psychiatric status. BASIS-32 was completed by patients at baseline and 12 month follow-up. HoNOS was completed by the researchers only at baseline in order to assess baseline differences between the experimental and control groups and to evaluate psychiatric status and psychosocial functioning from the mental health carers' point of view.

#### **1. Basis-32**

One of the main principles in choosing an appropriate outcome measure in psychiatric research **is the involvement of users of psychiatric services**. It was not possible to blind researchers to the intervention in this study because we had to assist patients in drafting the psychiatric advance statements. For this reason, in order to avoid bias, it was desirable that the main measure of mental health status was a self-report questionnaire. This does not remove the possibility of bias from the patient. Several patient-completed instruments exist but few had been designed

to provide a comprehensive assessment of mental state including symptoms of psychosis. Given the need to balance the utility of an outcome measure with a high response rate it was decided to use a brief self-report questionnaire that had recently been standardised. This was the 32-item Behaviour and Symptom Identification Scale (BASIS-32) (171). The scale was developed for research purposes on a psychiatric inpatient hospital population (n=387). Basis-32 asks for the degree of difficulty (on a 5- point scale: 0= no difficulty and 4=extreme difficulty) the patient has been experiencing with each item during the past week. The 32 items assess five major areas of difficulty and/or distress: relation to self/others, daily living/role functioning skills, depression/anxiety, impulsive/addictive behaviour (including substance abuse) and psychosis (see appendix 3).

The scale has good overall internal consistency ( $\alpha=.89$ ). The internal consistency for the five subscales is as follows:

- Relation to self and others  $\alpha= 0.76$
- Daily living and role of functioning  $\alpha= 0.80$
- Depression and anxiety  $\alpha= 0.74$
- Impulsive and addictive behaviour  $\alpha= 0.71$
- Psychosis  $\alpha= 0.63$

The authors (171) reported an average *test-retest reliability* across all items of 0.85. They tested the *concurrent validity* of the scale by correlating continued hospitalisation or rehospitalisation during the six months after admission and employment status at follow-up with Basis-32 scores at follow-up. Their results were statistically significant for the average Basis-32 score and for each of the subscales with the exception of impulsive and addictive behaviour. The authors reported good *discriminant validity* since the scores successfully discriminated between different diagnostic groups. Finally, they suggested that Basis-32 is sensitive to change in patients' symptoms and problem distress after treatment.

However, further research examining the reliability and validity of the scale has not always shown that the impulsive/addictive behaviour and psychosis subscales are adequate measures of these constructs for non-inpatient groups (173-176). Klinkenberg et al (1998) investigated the impact of changing the method of

administration (interview versus self-report) on the reliability and validity of the scale. Their sample consisted of 120 adults from 3 psychosocial rehabilitation programmes. They found good internal consistency and test-retest reliability on most subscales but the coefficients were higher in the self-report condition. Their results showed unacceptable internal consistency for the psychosis subscale of the interview version. Although validity correlations were good for the symptom subscales, they were poor for the functional domains (the subscales did not discriminate between diagnostic groups). They also found a trend for participants who completed the self-report version, to report somewhat greater distress on BASIS-32 subscales than participants who were administered the interview version (176).

Eisen et al (1999) examined the reliability, validity and sensitivity to change of the scale on outpatients' recipients (n=407). Psychiatric outpatients completed the BASIS-32 and SF-36 (a self-report survey designed to measure functional health status) at the beginning of an outpatient episode of care and 30 to 90 days later. They found that the full-scale internal consistency reliability was 0.95. They also found reliability coefficients above 0.60 for all subscales. However, two items on the psychosis subscale (hearing voices/seeing things and sexual activity/preoccupation) did not meet the 0.40 item-scale correlation criterion. As far as discriminant validity is concerned, the BASIS-32 scores differentiated between inpatient and outpatient samples. The specific subscale scores showed that outpatients with depression or anxiety reported significantly more difficulty on the depression/anxiety subscale. In contrast, the subscales of impulsive/addictive behaviours and psychosis failed to discriminate outpatients with substance abuse disorders and psychosis from those without such diagnoses. Finally, the construct validity and sensitivity to change were good (174).

In another study, Chun-Chung Chow et al (2000) assessed the cross-racial and cross-ethnic validity of the BASIS-32. The scale was administered at intake to 1,207 users of the City and County of San Francisco community mental health services. Fifty-two percent of their sample was white, 24% African American, 16% Asian American and 7% Latino American. In general, the results of the study showed moderate to high indicators of reliability and validity for the different

subscales. In accordance with the previously mentioned studies, the impulsive/addictive behaviour and psychosis subscales had somewhat lower reliabilities than the rest of subscales. The two subscales also were found to provide less discrimination than other subscales, often with more than 20% of respondents reporting none of the problems addressed in the items. The authors suggest that although their study provides strong evidence to support the usefulness of BASIS-32 with ethnic populations, their “evidence is limited by circumstances of administration, which include translation and provision of assistance by culturally and linguistically proficient clinicians. It says little about standardised translation of the instrument (173) (p.410).”

To summarise, the limitations that apply to other self-report questionnaires also apply to Basis-32. Interviewer and respondent biases are two of them. In addition, the scale was standardised on inpatients who were well enough to go through the interview. According to the authors they excluded 9% of patients who were too psychotic, confused or too unwell. Other types of measures or clinical assessment would be required for this type of population. Another limitation that I encountered was the length of time it takes to complete the scale (between 10-90 minutes). A lot of our participants found the instrument too long and tiring. Finally, although the scale is a useful outcome measure for a variety of populations (e.g. outpatients, ethnic populations), the scale needs further refinement especially in relation to the reliability and validity of the impulsive/addictive behaviour and psychosis subscales.

## **2. HoNOS-4**

In order to assess baseline differences between the experimental and control groups and to evaluate psychiatric status and psychosocial functioning from the mental health carers' point of view, the Health of the Nation Outcome Scales were chosen.

The Health of the Nation Outcome Scales is a set of 12 scales, each measuring types of patients' functional disabilities in health care practice, which is completed by professionals (172) (See appendix 4). The scale was developed to measure

health outcomes in response to the Department of Health's target to "improve significantly the health and social functioning of mentally ill people" (172). Each item of the scale measures a type of problem commonly presented by patients in mental health care settings and each is scored on a five-point scale ranging from 0 (no problem) to 4 (severe/very severe problem). The 12 items are intended to cover four areas of mental health: behaviour (1–3), impairment (4 and 5), symptoms (6–8), and social functioning/context (9–12). During the development of the scale patients were rated at the start of an episode of care and at discharge. The sample of patients comprised adults with severe mental illness attending in-patient and community psychiatric services. Ratings were carried out either by a nurse or a psychiatrist. Outcome was measured by comparing a patient's scores at the two points in time, using individual item scores, the dimensional sub-scores, and the total score. The authors claim that HoNOS is a unidimensional scale (172). However, Trauer's study (1999) indicated that low inter-item correlations suggest that the scale is not unidimensional and that the internal consistencies of the four subscales are poor (177). Trauer's study suggested a different subscale structure that fits the data better, differentiates diagnostic groups more accurately and accounts for more precise movements between in-patient and out-patient status (177). His model had five subscales, two of which were the same (social problems and impairment) as in the original HoNOS scale:

- Social problems
- Impairment
- Depression (items 2,7,8,9)
- Behaviour (items 1,3)
- Hallucinations/delusions (item 6).

According to Wing et al (1998), the information provided by the scales is of good quality and can be used to record clinical progress, for clinical audit and CPA reviews and clinical research. The authors also stated that HoNOS is reliable and sensitive to change. McClelland et al's study supported the authors' findings and added further evidence for a sufficient degree of both construct and criterion validity of the scale (178). However, other studies have questioned its reliability (179), sub-scale structure (177;179), sensitivity to change (180), appropriateness

for routine clinical use in busy psychiatric services (181;182) and usefulness in care-planning in day-to-day clinical practice, psychotherapy and psychological treatment services (182;183).

### **Hospital Service Satisfaction Scale**

Patients' satisfaction is an important variable in the process of care and its expected outcomes and has been studied widely since 1960. Recent studies suggested a significant association between patient satisfaction and treatment outcome and patient satisfaction and global reports of outcome (162;163). Patient satisfaction is a multidimensional concept that involves aspects such as overall satisfaction with health care, access to health care facilities, cost, overall quality, humaneness and competence of health carers (e.g. doctors, nurses, etc), provision of accurate and adequate information, food and physical facilities, visiting arrangements, bureaucratic procedures, handling of psychosocial problems, and patients' expectations regarding the services and amount, length or quantity of service (184;185). The study of patients' satisfaction was initially burdened with problems not only of an academic nature but also of political and socio-economic ones. In their review, Batchelor et al (1994) suggested that patient satisfaction research has been biased and in many cases counterproductive since patients have provided feedback on a service over which they "have little influence or any realistic choice but to remain even if dissatisfied" (p.23). However, with the introduction of the Patients' Charter and the National Service Framework in the mid 1990s, patient satisfaction studies have been taking into account patients' agendas as well as those of professionals who monitor the service provision.

The Hospital Service Satisfaction Scale I used was an adapted brief version of the Verona Satisfaction Scale (186) (See appendix 5). The reliability and validity of the version had been tested by Leavey et al in 1997 in patients at St Ann's Hospital (187). The scale consists of 9 questions (negative and positive) that aim to elicit spontaneous answers about the patients' experience in the previous year. These questions cover four main domains of care:

- Helpfulness of psychiatric care;
- Information and advice;
- Humane qualities of staff;
- Hotel aspects of hospital.



The alpha coefficient for these factors ranged from 0.72 to 0.86. The participants rated their satisfaction with the services on a five-point Likert scale (1=terrible, 2=mostly dissatisfied, 3= mixed, 4=mostly satisfied and 5=excellent).

**Preference for care booklet**

The advance statement was provided in the form of a "Preferences for Care" booklet (see also chapter one, section on preparing the booklet for further explanation and justification). As mentioned in chapter one, psychiatric advance statements appear under different names (e.g. advance agreement for future psychiatric treatment, anticipatory consent for treatment, Mill's will, Winick's proposals and Ulysses contracts). The choice of "Preferences for Care" booklet was made in order to avoid legal consequences due to the lack of statutory legislation covering psychiatric advance statements in this country. The front page of the booklet contained the name of the patient and his or her general practitioner, community psychiatric nurse, key-worker, consulting psychiatrist and social worker (see appendix 15). We included the trial centre's address in case the booklet became lost. The booklet contained seven statements on future preferences for treatment:

I notice I am becoming ill again when I.....
Things that happened just before I was placed on a section and/or started to become ill were.....
If I do seem to be becoming ill again I would like.....
I would like you to contact.....
I wouldn't want.....
If I have to be admitted to hospital again I would like.....
In hospital I would also like.....

**Table 11: Preference for care booklet**

The content of the directive was not intended to address compulsory admission directly. Rather it aimed to give patients an opportunity to consider their future treatment on a wider basis, thereby increasing their trust and compliance and ultimately reducing the need for compulsory treatment. One might argue that the preference for care booklet was not really an advance statement because it did not direct, guide and impel toward a specific action or goal which in this case is compulsory re-admission. However, the questions in the preference for care

booklet and the answers provided by the patients (see results section) were intended to provide a clear guide for the professionals about what a patient would like to be done if he or she becomes ill again and needs hospitalisation and treatment. This is especially true for questions 1 and 2 that can be used as means of opening discussions with the patient into early warning signs. The choice of the statements in the preference for care booklet are also in accordance with the guidelines of the report of the expert committee on the review of the Mental Health Act 1983 which states (28):

12.13..... It (an advance statement about care ) would address the patient's treatment preference (if any) in relation to any possible future care and treatment for mental disorder, and it would have to be taken into account as a capable expression of the patient's preferences should treatment become necessary at a future point when the patient has lost capacity.

In order to avoid overestimation of the legal effects of the booklet, a rider placed at the end of the booklet indicated that professionals were not legally bound to comply with the preferences for care, if, for instance, the patient was subsequently recommitted (See appendix 15). Again some may argue that the disclaimer undermined the importance of the directive. However, expert legal advice taken at the outset of the trial meant that there was little option but to include it, given the uncertain legal status of advance statements in England and Wales at that time.

### *Follow-up materials*

Twelve months after discharge we completed the following measures again:

1. **The Basis-32.**
2. **The Hospital Service Satisfaction Scale for measurement of satisfaction with treatment over the 12 months follow-up.**
3. **The Self-Efficacy Scale (Schwarzer 1993).**
4. **Semi-structured interview for patients on use of the advance statements**
5. **Semi-structured interview for consultant psychiatrists and key-workers on their awareness of the statement, its use, and whether it could be improved**

### **The Self-Efficacy Scale (Schwarzer 1993)**

The Self-efficacy scale assesses people's "general beliefs in their ability to respond to and control environmental demands and challenges" (147). This is the first study that measured the self-efficacy beliefs and expectations of sectioned patients. Although I did not obtain any data on patients' self-efficacy at baseline due to practical difficulties, evidence from smoking cessation programmes suggests that pre-treatment self-efficacy does not predict relapse but post-treatment self-efficacy does (see also chapter 3 on self-efficacy) (129).

The scale contains ten general self-efficacy items (items 1-10 developed by Schwarzer in 1992), two specific self-efficacy beliefs (items 11. I can manage my own mental health and 12. I can make decisions about my future care) and two outcome expectations (items 13. If I need hospitalisation in future I can voluntarily admit my self and 14. I can contact my GP/KW/outpatient clinic, the next time I begin to relapse) (developed by me) (See appendix 11). It is a self-report measure that normally takes five to ten minutes to complete. Patients were required to indicate the extent to which each statement applied to them. For each item there is a four choice response from 'Not at all true' which scores 1 to 'Exactly true' which scores 4. The score for each of the fourteen items are summed to give a total score. The higher the score the higher the individual's sense of self-efficacy. The internal consistency of the original scale was high ( $\alpha=0.82$  to  $0.93$ ). Cronbachs alpha coefficient is high for both the short (ten item) and longer (fourteen item) version of the self-efficacy questionnaire, being 0.91 and 0.91 respectively. This indicates that both versions have satisfactory internal consistency, and conclude that the shorter version is satisfactory to use. Test-retest reliability (0.47 for men and 0.63 for women) was moderate (147). The concurrent validity of the scale was established by using correlations with other tests (147). Positive correlations were found with measures of self-esteem (0.52), internal control beliefs (0.4) and optimism (0.49)(147). Negative correlations were found with general anxiety (-0.54), performance anxiety (-0.42), shyness (-0.58) and pessimism (-0.28)(147). Schwarzer (1993) assessed the predictive validity of the scale in a one-year follow-up of East German migrants (147). He found that the scale correlated positively

with measures of self-esteem (0.40) and optimism (0.56) in women. However, the correlations in men were weaker: self-esteem (0.20) and optimism (0.34) (147).

**Semi-structured interview for patients and mental health professionals on use of the advance statements**

In addition to the three psychometric scales (Basis-32, Hospital Satisfaction and Self-efficacy), we also designed two semi-structured interview forms, one to elicit and record patients' views on the usefulness of the advance statements (see Appendix 12) and the other to elicit consultant psychiatrists' and CPA key-workers' views (see Appendix 13). Professionals received one questionnaire per patient.

## **Procedures**

The study was funded by the Responsive Funding Division of the NHS Research and Development Executive (former North Thames Regional Health Authority).

### ***Ethical considerations***

The study received approval of the ethical practices sub-committees of the Royal Free Hampstead NHS trust and Enfield and Haringey NHS trust. The study was conducted according to the Helsinki declaration on research into human subjects (including amendments) that requires obtaining and documenting informed consent and ensuring archiving of patient identity codes for at least 15 years. All study records (except the preference for care booklet) were kept confidential. In accordance with the Data Protection Act, participants' names were not entered onto the computer database.

An ethical issue that became apparent during the study was that of implicit withdrawal of consent. Participants were free to withdraw at any time and a statement of wish to withdraw resulted in cessation of contact. However, a number of patients who initially consented to participate in the study, avoided my efforts to follow them up without explicitly withdrawing consent. After a meeting with the research team, it was decided not to contact participants who failed to keep three follow up appointments.



### ***Preparing the setting and the hospital staff***

Once ethical approval for the study was obtained, the ward managers of both psychiatric hospitals were approached to discuss the study. Following their approval, we attended their staff meetings and explained the study to the rest of the ward staff. In addition, a number of handover meetings and Care Programme Approach meetings were attended.

Extensive discussions took place with managers, consultant psychiatrists and nurse managers about the study to ensure they were fully informed and prepared for the trial during the first six months of the trial. Although it would have been useful to incorporate the directives into the formal CPA process, clinicians did not think that this was warranted at the stage the trial was designed.

## *Preparing the patients*

### **Feasibility study**

During the first six months of the trial (September 1996 to February 1997) a small feasibility study was carried out in order to pilot the materials and the procedures used in this study. The researcher who carried out the feasibility study recruited competent sectioned patients from the Royal Free and St Ann's hospitals. She recruited 26 patients of whom 11 completed the interviews (6 controls and 5 preference for care) and 15 aborted the interviews (either refused half way or were too ill). Between February and April 1997 the materials and procedures were revised and the final version of the preference for care booklet was printed.

### **Main trial**

When recruitment started, participants were seen individually by myself and another researcher who informed them about the purpose of the study and what would be involved for them. A standard written form with a summary of the study was given to all potential participants (see appendix 1). Participants were also informed about accessibility of their local service users' groups for further advice on any related issues. Local service users groups were informed about the study and I and my supervisor talked to the groups regularly throughout and after the trial. Competence to enter into an agreement was an important prerequisite for the study. Members of the clinical team responsible for each patient's care were consulted in relation to their competence prior to the interview. **Only competent patients were approached.** In addition, because there was no single established test of competence to consent to treatment in British Law at that time, it was decided that each patient would be assessed on the following:

- Their capacity to understand information necessary to complete a preference for care statement, which included understanding the necessity for care and what the preference for care document is.
- Their awareness of their situation and that they are receiving treatment.
- Their understanding that failure to complete a preference for care statement would not affect their care in any way.

Evaluation of the above points were incorporated in the interview process in the form of questions and patients were asked to re-state their understanding of the

issues involved in the study in their own words when there were doubts about their understanding.

### ***Baseline data collection***

During baseline assessments, data were collected from patients in the form of questionnaires and from their hospital notes. I and the other researcher visited the psychiatric wards weekly and made lists of sectioned patients who were near discharge from section. After discussions with nursing and medical staff, eligible patients were approached and asked to give consent to participate in the study. Each patient who initially accepted to participate was briefed further about the study and asked for written informed consent (see appendix 2). Brief demographic data were obtained for those patients who refused to participate. After informed consent was obtained, each participant was asked to complete the BASIS-32 and the Hospital Service Satisfaction Scales.

After randomisation, participants in the preference for care group were encouraged to complete and sign four copies of the preference for care booklet. Participants who did not wish to write in the booklet themselves, dictated their preferences to me and the other researcher. Only patients who were able to read and write English were included in the study. In the cases where myself and the other researcher wrote the statement, the patient read the statement and then signed the document. The same process was followed for the rest of the copies that had to be read and signed by the patient before they were disseminated. This process is in agreement with both the report of the expert committee on the review of the Mental Health Act 1983 and the BMA code of practice (28;188). Each patient was asked to keep a copy of the booklet in a safe place. We gave one copy to the key worker and general practitioner as well as placing one in the front of the hospital records.

After the participant left the session (which could last up to two hours), I and the other researcher with the help of a member of the ward staff who worked closely with the participant, completed the HoNOS scale. Finally, information (see appendix 6) was gathered from the case notes.

All patients continued to receive standard community psychiatric care.

### ***Follow-up data collection***

One year from baseline I went through the following procedure:

1. I gathered information from the participants' notes in order to complete the follow-up form (appendix 14). The case notes gave me an idea where I would find most of the participants.
2. The participants were contacted by telephone and/or letter and reminded about the last phase of the study. An appointment was made for an interview either in their homes, rehabilitation centre or hospital.
3. The participants in both groups were given the BASIS-32, Hospital Service Satisfaction and Self-efficacy scales to complete. Those in the intervention group were shown their preference for care booklet and were given to complete the structured questionnaire about the usefulness of the booklet (see appendix 12).
4. The Care Programme Approach key-worker and consultant of the participants in the intervention group were sent a letter reminding them about the follow-up phase of the study and a semi-structured questionnaire per patient about the usefulness of the directives (see appendices 10 and 13).

## **Statistical analysis**

### ***Pre-trial sample size and power calculation***

Hospital data for sectioned admissions were used to calculate the sample size. Hospital data for the year before the study indicated that 50% of patients discharged from a compulsory admission were re-admitted within 12 months, 60% of whom were re-admitted compulsorily. That means 30% of all patients were readmitted compulsorily within one year. We estimated that detecting a reduction in the rate of compulsory readmission to 10% or less in the advance statements group (compared to 30% in the control group) at 90% power and the 5% level of significance would require 80 patients in each group.

### **Rationale for power calculations**

Sample size calculations were based on the admissions data in the year 1996, collected at the hospital where the trial was based. The admissions data (same setting, similar time period) from that year should therefore have been a reasonable predictor of the future rate at which trial participants would have been readmitted. Nevertheless, we cannot exclude the possibility (with the benefit of hindsight) of 1996 being an unusual year, or that there may be unpredictable year-to-year fluctuations in readmission rates, depending on the case mix for that particular period. Sample size calculations have to be based on historical data, and it is not possible to take into account variations that can later affect readmission. Moreover, readmission rates of 50% are not uncommon in psychiatry, Kisely et al (2004) found that up to 72% of their patients with compulsory treatment orders were readmitted within a year (189).

The decision to look for an absolute reduction of 20% in the readmissions rate (from 30% to 10%) is based on the view that this would represent a palpable, clinically meaningful benefit which would be appreciated both by clinicians and patients. This level of reduction would also be regarded as sufficient to have a significant impact on health service resources, whereas a lower level of benefit may probably go unnoticed.

### ***Data handling***

Data entry and data checking were undertaken using the data entry module of Epi-Info (v6.01). The results of each questionnaire for baseline and follow-up and the administrative and demographic data were entered onto individual Epi-Info files. Each file was associated with a check file to identify out-of-range data values and essential missing data. Each Epi-Info file was checked for accuracy by double entry by myself and the other researcher. These files were then exported to SPSS (1998) data files and were combined to provide a comprehensive database of variables (190). At this point, I carried out a second comprehensive check of data by checking each data record against the original data record to ensure the database was as error-free as possible.

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

I first ran an exploratory data analysis in order to check the distribution and detect outliers. All patients were analysed in the group to which they were allocated in an intention to treat analysis. As already described, the primary outcome was the number of people compulsorily readmitted under the Mental Health Act during follow-up. In the analysis of other outcomes I made group comparisons using standard t-tests for approximately normal data, Mann-Whitney tests for ordinal non-parametric distributions and the Chi-squared statistic for categorical data. I reported grouped medians for ordinal non-parametric data. The grouped median is the median weighted by the frequency of data in the adjacent categories and is particularly useful for extreme scores such as days spent in hospital or on section. I used Cronbach's alpha to test the internal consistency of the adapted Hospital Service Satisfaction Scale ( $\alpha = 0.9$ ) and self-efficacy scale ( $\alpha = 0.9$ ). Analyses of covariance (controlling for baseline values) of Basis-32 and Hospital Service Satisfaction scores were performed on log-transformed data. Univariate logistic regression was used, firstly to analyse each potential explanatory variable independently to give some indication as to factors that may be important for re-admission. A multivariate approach also using logistic regression was taken in order to build a model that accounted for any interaction terms and included all relevant explanatory variables/potential confounders. The multivariate model was used to estimate and test the influences of multiple variables on the risk of readmission. This multivariate analysis involves the simultaneous statistical evaluation of the relationships among the multiple measured properties (e.g. age, lives alone) of the trial participants, and the rate of readmission. The most parsimonious model, which included adjustment for the variable 'group', was chosen, based on likelihood ratio tests. Where data were missing listwise or casewise approach was used.



### ***The content of psychiatric advance directives***

As mentioned in chapter 1, only a handful of studies have looked at the content of psychiatric advance directives (18;25;85;90;92). The preference for care study is the first one to look at the content of sectioned patients' psychiatric advance statements. As Brown and Lloyd (2001) suggest, during the exploratory stages of a research project/area, qualitative methodology is an appropriate means for examining policy implementation and collating user views. Since we know very little about the preferences for care of psychiatric patients in general and sectioned patients in particular, we decided to explore the content of psychiatric advance statements using content analysis. Content analysis was considered the most appropriate method for the type of responses we obtained from the patients (191-193).

### **Content analysis**

“Content analysis is the most deductive of all forms of data analysis....The categories of analysis are developed through logical deduction from the pre-existing theory....Content analysis as with any other form of data analysis, begins with the identification of the population from which units are sampled.... Content analysis next defines the units of analysis and the categories into which these will be placed. Data analysis involves reviewing each unit of analysis and categorising it according to the predefined categories. The occurrences are then counted and comparisons are made, often using statistical or quantitative methods. The final stages of content analysis is the interpretation of results.” (193) (pp 82-83) In other textbooks, the process of counting the instances of each unit under a category and producing percentages is also known as *tabulation* (192).

### **Content analysis of the preference for care booklets**

The data obtained from the patients' booklets (see appendix 15) composed our sample that was read and content analysed independently by myself and another researcher (191-194). Patients' responses comprised the units of analysis which were entered under the seven preference for care booklet's headings into a word processing package. After several readings, each researcher created her own

codes/themes that emerged from the data which we then compared (see chapter 8 for more details on the development of codes/themes). Any discrepancies which were found were discussed and data were recoded where appropriate. We then counted the number of responses under each category independently and transferred the data to SPSS (version 9) in order to obtain the distribution of responses in each category. Seventy-nine advance statements were analysed.

## **Chapter summary**

Overall the study was carried out smoothly without major difficulties and unexpected events. Most of the patients who participated in the study expressed very positive views about the idea of completing the preference for care booklet. Some of them found the process of completing all the scales plus the preference for care booklet tiring but educative nonetheless (some interviews took up to two hours). Overall, the psychiatric staff was helpful and supportive. In the next section the results in relation the main and secondary outcomes will be presented as well as the findings from the preference for care booklets and patients' and mental health professionals' views on the usefulness of the booklets.

## **PART III**

# **RESULTS**

### **Introduction**

Part III will be divided into two chapters. In chapter 7 I shall present the quantitative results of the study that provide answers to the hypotheses the preference for care study set out to test, while in chapter 8 the findings from the preference for care booklets and patients' and mental health professionals' views in relation to the usefulness of the booklets will be presented.

## **Chapter 7**

### **Quantitative results**

This section begins with the CONSORT statement which is followed by the description of the population from which the sample of the preference for care study was drawn and the results of the randomisation process. This is followed by the results of the analysis in relation to the main hypothesis of the study, the profile of patients who did not complete the study and the main predictors of outcome for the whole trial sample. Finally, the results in relation to secondary outcome measures are presented which are followed by the results in relation to the last two hypotheses of the preference for care study.

## Recruitment

The results of the study are reported according to the CONSORT statement on reporting randomised controlled trials (154). The flow diagram below gives an outline of the attrition during the trial (Figure 5).

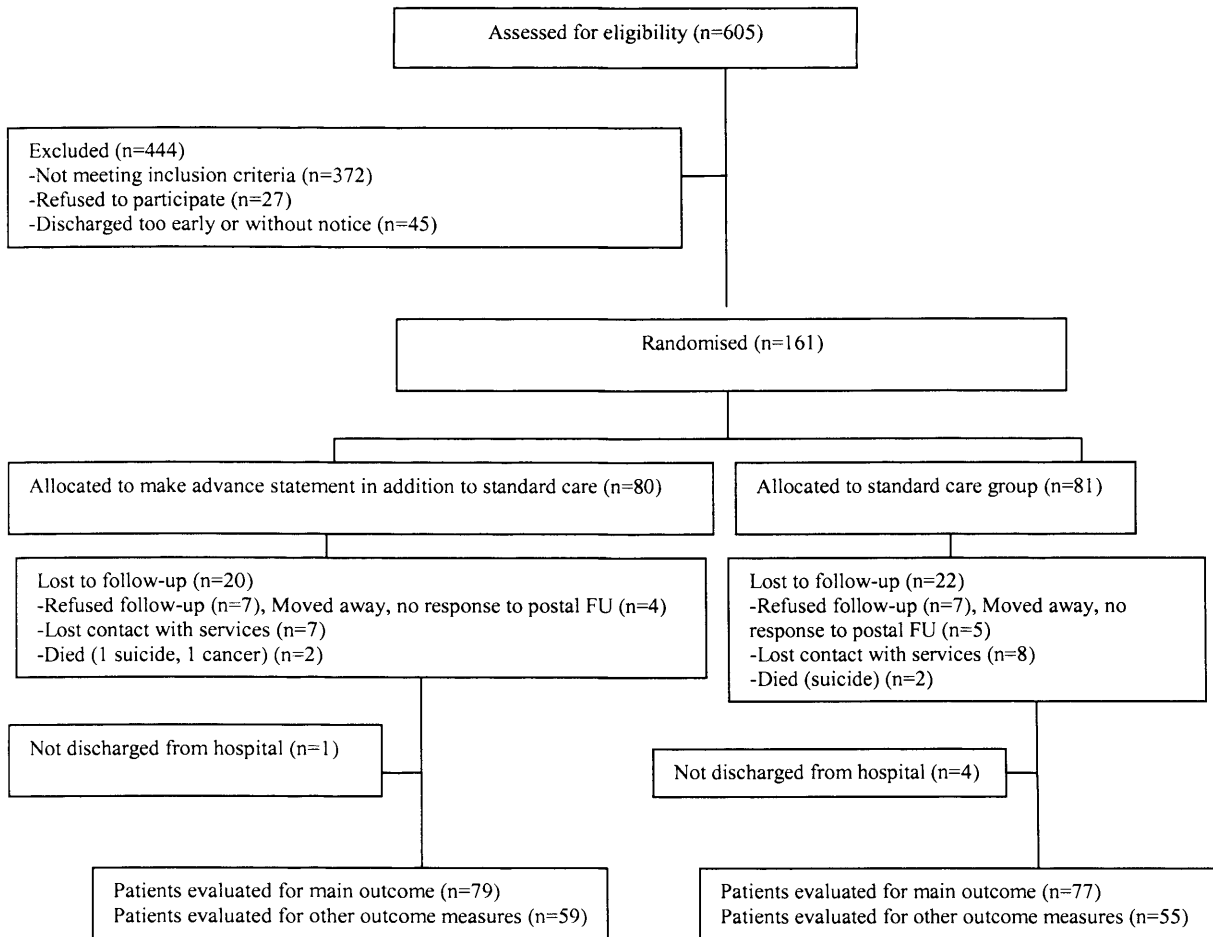


Figure 5: Flow diagram of recruitment and attrition

## **Exclusions**

Six hundred and five patients were admitted under section of the Mental Health Act during the period of recruitment of whom 161 entered the trial (Figure 1). All except six (who were not competent) of the 372 not meeting inclusion criteria were transferred onto a further commitment order or to another hospital, their section was renewed and were not discharged from hospital, they suffered from organic and psychoactive substance use disorders, could not read and write English. There were no significant differences in sex and age between those considered and those eventually taking part or between the participants who entered the trial and those who refused.

## **Effectiveness of randomisation**

Table 12 summarises the demographics of the sample according to experimental and control groups. There were no major baseline differences in age, sex, ethnicity, marital status, household composition or employment between the two arms of the trial, confirming that the randomisation appeared to have been conducted satisfactorily.

	<b>Advance statements group (n=79)</b>	<b>Control group (n=77)</b>
<b>Mean age in years</b>	35.5 (SD 11.3)	36.3 (SD 12.6)
<b>Gender</b>		
Male	42 (53%)	51 (66%)
<b>Ethnic group*</b>		
White	43 (54%)	48 (62%)
Black	22 (28%)	24 (31%)
Other	14 (18%)	5 (6%)
<b>Marital status</b>		
Single	50 (63%)	54 (70%)
Married	10 (13%)	4 (5%)
Divorced/separated	16 (20%)	16 (21%)
Widowed/other	3 (4%)	3 (4%)
<b>Household composition</b>		
Lives alone	11 (14%)	7 (9%)
Lives with partner	16 (20%)	12 (16%)
Lives with parent	32 (40%)	41 (53%)
Other	20 (25%)	17 (22%)
<b>Employment status #</b>		
Unemployed	31 (39%)	29 (38%)
Sickness benefit	34 (43%)	39 (51%)
Employed (f/t & p/t)	4 (5%)	5 (6%)
Other	10 (13%)	4 (5%)

**Table 12: Demographic characteristics at baseline**

\* Black = African Caribbean, Black African, other Black.

Other = Indian, Pakistani, Bangladeshi, Chinese, other Asian.

# Other = home-manager, retired, student and other



## **Baseline mental health**

There were no differences in previous hospitalisation, diagnosis, symptoms (Basis-32) or satisfaction with services (see Table 13), between the two trial arms. Further analysis of the Basis-32 and HoNOS subscales did not show any significant differences between the experimental and control groups. The average Basis-32 and HoNOS scores as well as the scores obtained from their subscales are typical of the average scores reported for acute care patients in other studies that used the same instruments (166).

	<b>Advance statements group (n=79)</b>	<b>Control group (n=77)</b>
<b>Diagnosis</b>		
Psychosis	50 (63%)	49 (64%)
Depression/bipolar disorder	22 (28%)	22 (29%)
Other	7 (9%)	6 (8%)
<b>Basis-32 (grouped median)</b>	0.63 min=0, max=2.84	0.68 min=0, max=2.63
<b>Mean Hospital satisfaction Score</b>	30.34 (SD 7.4)	28.5 (SD 7.5)
<b>Mean HoNOS score</b>	44.30 (SD14.4)	45.30 (SD 14.2)
<b>*Pre-admission social &amp; role performance</b>		
Above average	10 (13%)	9 (12%)
Average	28 (35%)	23 (30%)
Below average	36 (46%)	37 (48%)
Markedly below average	5 ( 6%)	8 (10%)
<b>Mental Health Act status</b>		
Section 2	25 (32%)	17 (22%)
Section 3	52 (66%)	59 (77%)
Section 4	2 (2%)	1 (1%)
<b>Number of antipsychotic medications prescribed at discharge</b>		
0	9 (11%)	4 ( 5%)
1	53 (67%)	62 (80%)
2	16 (20%)	11 (14%)
3	1 (1%)	0

**Table 13: Clinical characteristics at recruitment.**

\*Pre-admission social & role performance is measured by the Health of the Nation Outcome Scales

Patients in the advance statement group, however, had spent less time in hospital during the index admission than those in the control group (Table 14).

	<b>Advance statements group, n=79, Grouped median (min, max)</b>	<b>Control group, n=77, Grouped median (min, max)</b>
<b>1) Number of days in hospital index admission*</b>	94 (13, 545)	123 (13, 1,546)
<b>2) Number of admissions in previous 5 years</b>	1.3 (0, 17)	1.4 (0, 10)
<b>3) Days in hospital in 12 months prior to index admission</b>	4.5 (0, 365)	13 (0, 350)
<b>4) Number of admissions in year before index admission</b>	0.6 (0, 3)	0.7 (0, 4)

**Table 14: Baseline characteristics concerning hospital care**

\* Mann Whitney U = 2427, p = 0.03

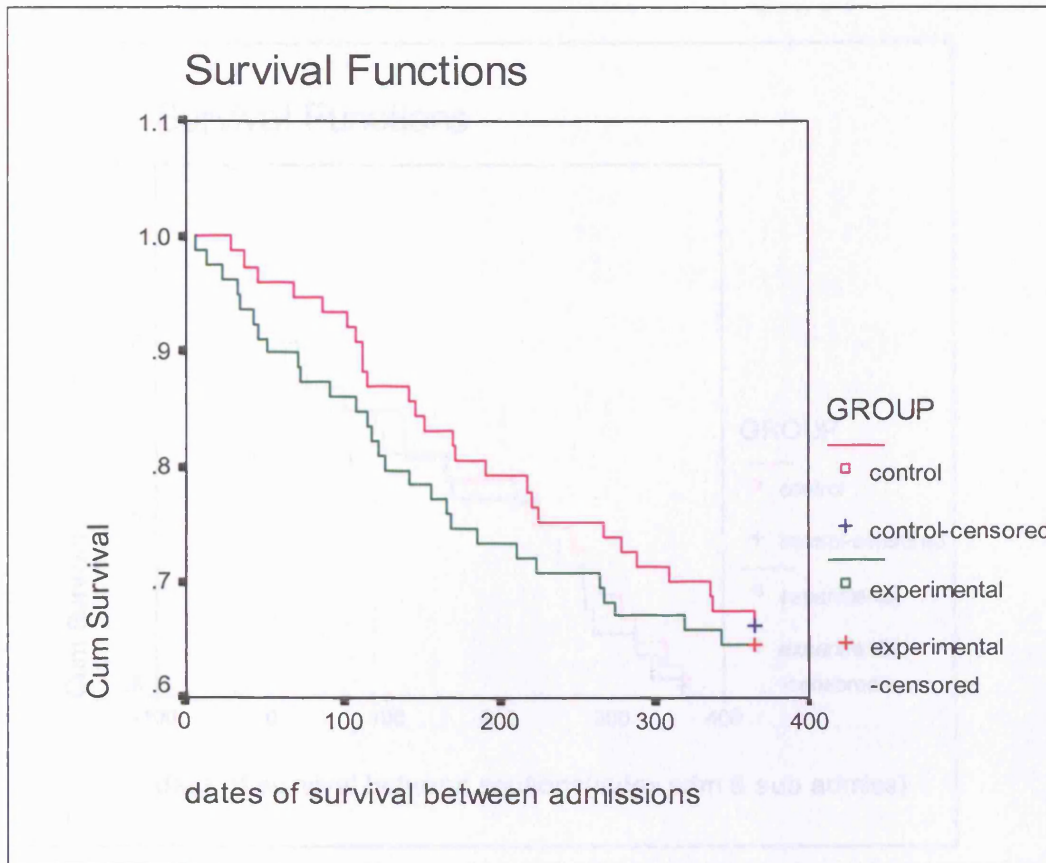
## **Follow-up rates**

### ***Main Outcome***

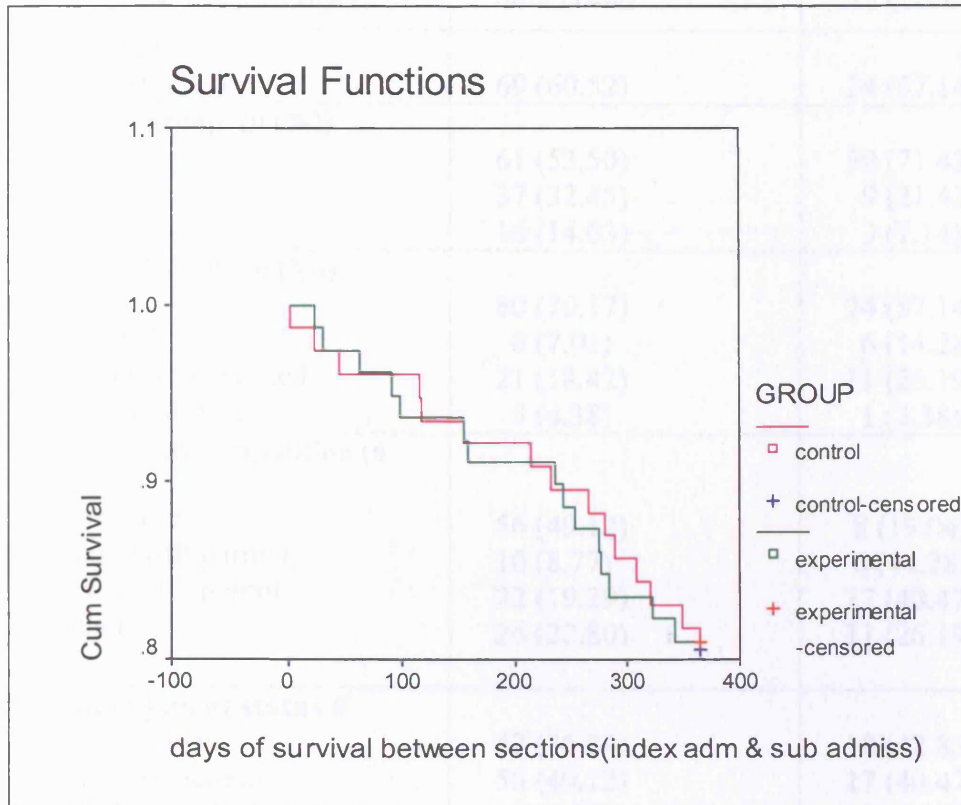
In order to test the main hypothesis of the preference for care study, I obtained data on the principal outcome for all randomised patients. Five patients (experimental= 2, control= 3) were not discharged from hospital during the follow-up period and were removed from the analysis. I conducted face-to-face assessments of 59 (75%) patients in the advance statements and 55 (71%) in the usual care arms 12 months after recruitment (figure 5). There were no statistically significant differences in sex, age, ethnicity or primary diagnosis between those interviewed at follow-up and those not contacted (see Table 15). Nor was there any difference in the primary outcome between those contacted and those not contacted at follow-up.

Fifteen participants (19%) in the experimental and 16 (21%) in the control group were readmitted to hospital under section within one year of discharge (Chi-squared=0.08, df=1, p=0.8). Survival analysis supports this conclusion across all time points (see Graphs 1 & 2).

Graph 1: The X axis (dates of survival between admissions) shows the time from first discharge (point 0), the Y axis (cum survival) shows the percentage of patients who were out of hospital after first discharge.



Graph 2: The X axis (dates of survival between sections) shows the time from first discharge from section (point 0), the Y axis (cum survival) shows the percentage of patients who were not on section after first discharge.



**Demographic characteristic of participants lost to follow-up**

	<b>Interviewed Participants (n= 114)</b>	<b>Not interviewed Participants (n=42)</b>
<b>Mean age in years (s.d.)</b>	35.5 (12.5)	37 (10.48)
<b>Gender</b>		
Male (n (%))	69 (60.52)	24 (57.14)
<b>Ethnic group*(n (%))</b>		
White	61 (53.50)	30 (71.42)
Black	37 (32.45)	9 (21.42)
Other	16 (14.03)	3 (7.14)
<b>Marital status (n (%))</b>		
Single	80 (70.17)	24 (57.14)
Married	8 (7.01)	6 (14.28)
Divorced/separated	21 (18.42)	11 (26.19)
Widowed/other	5 (4.38)	1 (2.38)
<b>Household composition (n (%))</b>		
Lives alone	56 (49.12)	8 (19.04)
Lives with partner	10 (8.77)	6 (14.28)
Lives with parent	22 (19.29)	17 (40.47)
Other	26 (22.80)	11 (26.19)
<b>Employment status #</b>		
Unemployed	42 (36.84)	18 (42.85)
Sickness benefit	56 (49.12)	17 (40.47)
Employed (f/t & p/t)	6 (5.26)	3 (7.14)
Other	10 (8.77)	4 (9.52)
<b>Mental Health Act Status at baseline (n (%))</b>		
S2	26 (22.80)	16 (38.09)
S3	85 (74.56)	26 (61.90)
S4	3 (2.6)	

**Table 15: Demographic characteristic of participants lost to follow-up**

\* Black = African Caribbean, Black African, other Black.

Other = Indian, Pakistani, Bangladeshi, Chinese, other Asian.

# Other = home-manager, retired, student and other

### Predictors of outcome for the whole trial sample

Table 16 shows the individual odds ratios from univariate analyses of potential predictor variables, with their associated 95% confidence intervals and p-values. It appears from this table that having two or more previous admissions increases the odds of re-admission to almost two and a half times that of someone who has had one or no previous admissions, (95% confidence interval 1.09 to 5.62). Also, someone who lives alone is approximately twice as likely to be re-admitted as someone who has a different household composition is. No other variables were significant.

	<i>Odds Ratio</i>	<i>95% Confidence Interval</i>	<i>p-value</i>
Randomised arm (Experimental vs. Control)	0.89	0.41 to 1.96	0.78
Gender (Male vs. Female)	1.30	0.57 to 2.93	0.54
Ethnicity (Non-white vs. White)	1.01	0.46 to 2.25	0.97
Primary Diagnosis (Dep/ Mania/ Bipolar/Other vs. Psychosis)	1.12	0.50 to 2.52	0.78
Household (Lives Alone vs. Other)	2.08	0.93 to 4.65	0.07
Living (With Help vs. Independent)	0.66	0.30 to 1.48	0.31
Relation to Carer (Relative/partner vs. Other) <sup>1</sup>	1.99	0.66 to 6.02	0.22
Employment (Not-Employed vs. Employed)	2.05	0.25 to 17.04	0.51
<b>No. Previous Admissions ( 2 or more vs. none or 1)</b>	<b>2.54</b>	<b>1.13 to 5.70</b>	<b>0.02</b>
Age Group (25-54 vs. under 25)	0.63	0.25 to 1.63	0.34
Age Group (over-54 vs. under 25)	0.31	0.06 to 1.65	0.17
Marital Status (Married vs. Single/divorced/separated)	1.70	0.50 to 5.85	0.4

<sup>1</sup>n=56 missing data from this group

**Table 16: Univariate analysis of predictors of re-admission**



## Secondary Outcomes

### Subsequent admissions

Table 17 presents the results of the statistical analyses that were performed to test secondary outcome measures such as the number of subsequent compulsory admissions, days spent on a section, number of patients' readmitted voluntarily or days spent voluntarily in hospital. There were no significant differences between the two groups in either of the above.

	<b>Advance statements group (n=79)</b>	<b>Control group (n=77)</b>
<b>Number of subsequent Sections of the MHA</b>		
0	64 (81%)	61 (79%)
1	9 (11%)	11 (14%)
2	4 ( 5%)	5 ( 6%)
> 2	2 ( 2%)	0
<b>Grouped median</b>	0.2 (range 0, 4)	0.22 (range 0, 2)
<b>Days on subsequent sections</b>		
0	64 (81%)	61 (79%)
1-100	10 (13%)	14 (18%)
101-365	5 (6%)	2 (2%)
<b>Days as an inpatient on a subsequent voluntary admission</b>		
0	52 (66%)	49 (64%)
1-100	20 (25%)	22 (29%)
101-200	6 (7%)	5 (6%)
201-365	1 (1%)	1 ( 1%)
<b>Number of patients Re-admitted voluntarily</b>	13 (16%)	12 (16%)

Table 17: Secondary outcome measures

### **Self-efficacy**

Statistical analyses to test the second main hypothesis of the study showed that there was no difference in the total self-efficacy score at follow-up (advance statements grouped median 42.66; control arm grouped median 42.25) and the self-efficacy subscales between the two groups.

### **Mental health at follow-up and patients' satisfaction with the mental health services they received**

Table 18 presents the results of the statistical analyses that were performed to test patients' mental health status at follow-up and the third main hypothesis of the study regarding the patients' satisfaction with the mental health services they received.

Patients reported less symptoms of mental illness at baseline and more symptoms at follow-up as the analysis of their scores on the BASIS-32 showed. However, there was no indication on other parameters that patients' clinical state had deteriorated by the time of follow-up.

There were no significant differences between the two groups in relation to their satisfaction with the mental health services they received (see Table 18).

	<b>Baseline score</b>	<b>Follow-up score</b>
<b>BASIS-32</b>	<b>Grouped median (min, max)</b>	<b>Grouped median (min, max)</b>
Advance statements group (n=59)	0.63 (0, 2.84)	0.81 (0, 3.34)
Control group (n=55)	0.68 (0, 2.63)	0.62 (0, 3.25)
<b>Hospital Satisfaction</b>	<b>Grouped median (min, max)</b>	<b>Grouped median (min, max)</b>
Advance statements group (n=59)	31 (15, 45)	29 (9, 45)
Control group (n=55)	29 (10, 45)	31 (9, 44)

**Table 18: Mental health at follow-up**

### **Basis-32 and hospital satisfaction for non-completers**

Mann-Whitney tests for non-completers showed no difference between the two groups regarding their Basis-32 scores but a significant difference ( $p < 0.04$ ) between their hospital satisfaction scores with the preference for care group expressing greater and the control lower satisfaction with services.

### **Chapter summary**

In this chapter I have presented results relating to the demographic and clinical characteristics of the study sample and the effectiveness of randomisation. I have also presented results concerning the primary and secondary outcome measures. In the next chapter I will present the findings from the psychiatric advance statements and the patients' and mental health professionals' views in relation to the effectiveness of the statements.

## **CHAPTER 8**

### **Findings from the Preference for Care booklet and the patients' and mental health professionals' views on the usefulness of the booklet**

So far, there has been very little empirical research in this country relating to the content of sectioned patients' psychiatric advance statements. Two of the aims of the preference for care study were; first, to explore the content of psychiatric advance statements of sectioned patients and second, to explore the patients' and mental health professionals' views in relation to the usefulness of such documents.

## The content of the Preference for Care booklet and the development of codes/themes

There were seven statements in the preference for care booklet (see Table 19).

Statement 1: “I notice I am becoming ill again when I.....”
Statement 2: “Things that happened just before I was placed on a section and/or started to become ill were...”
Statement 3: “If I do seem to be becoming ill again I would like...”
Statement 4: “I would like you to contact...”
Statement 5: “I wouldn’t want...”
Statement 6: “If I have to be admitted to hospital again I would like...”
Statement 7: “In hospital I would also like...”

**Table 19: Content of the Preference for Care Booklet**

Each patient could give up to three open responses under every statement of the preference for care booklet (see appendix 15 for an example of a completed booklet). For example, one patient (who will be called P15) wrote under statement 1: “I notice I am becoming ill again when I...”

- *“hear voices saying bad things”*
- *“get a headache and my brain goes round”*
- *“cannot eat or sleep”*

Another patient (who will be called P19) wrote under statement 1: “I notice I am becoming ill again when I...”

- *“can not keep my place tidy”*
- *“neglect my self”*
- *“hear voices”*

The first open response from P15 (“hear voices saying bad things”) was coded as Positive psychotic symptoms; the second open response from P15 (“get a headache and my brain goes round”) was coded Physical/somatic problems; the third response from P15 (“can not eat or sleep”) was coded Mood/anxiety, emotional disturbance; and so on. The process of creating codes/themes for each patient’s response continued until no new codes emerged and ‘saturation’ was reached, at which point new patients’ responses could be accommodated by existing categories (192-194). To avoid having too many codes under each statement of the preference for care booklet we decided to merge codes such as positive and negative psychotic symptoms into one code which appears under the name:

Positive or negative psychotic symptoms (see Table 20). The number of responses under each code/theme was then counted and the percentages of total responses were calculated.

*The findings from the Preference for Care booklet*

**Statement 1: “I notice I am becoming ill again when I...”**

Five major categories of response were identified for the first statement, "I notice I am becoming ill again when..." (Table 20). Other categories included becoming ill again due to alcohol or drugs (n=7); due to confusion, relationship problems or financial problems (n=5); due to missing appointments or not taking medication (n=4); and due to committing self-harm or expressing suicidal ideas or behaviour (n=3).

Positive or negative psychotic symptoms	32 (41%)
Physical/somatic problems	28 (35%)
Mood/ anxiety, emotional disturbance	27 (34%)
Aggression / irritability/ anger	22 (28%)
Altered behaviour	17 (22%)

**Table 20: Responses to preference for care statement 1: "I notice I am becoming ill again when ..."**

**Statement 2: “Things that happened just before I was placed on a section and/or started to become ill again were ...”**

Statement two produced responses that were coded and analysed thematically under the headings in Table 21. These responses focused on symptoms such as chronic illness and its triggering factors such as missing treatment or not taking prescribed medication, and also relationship problems.

Medication/appointments problems	18 (23%)
Positive or negative psychotic symptoms	15 (19%)
Relationship problems	15 (19%)
Aggression / irritability/ anger	13 (16%)
Social/ financial/ work/health problems	13 (20%)
Altered behaviour/routines	11 (14%)
Mood/ anxiety disturbance	10 (16%)
Self harm/ suicidal ideas/behaviour	6 (8%)
Use of alcohol or drugs	6 (8%)
Trouble with police/others	6 (8%)
Confusion/isolation/withdrawal	4 (6%)
Physical/ somatic problems	4 (6%)

**Table 21: Responses to preference for care statement 2: "Things that happened just before I was placed on a section and/or started to become ill again were ..."**

For example, patient 20 wrote:

- *“I stopped my medication”*;
- *“I had an argument with my girlfriend”*.

Patient 102 wrote:

- *“talk too much about religion”*;
- *“don't sleep”*;



- “show inappropriate behaviour such as lying down on the floor and give money away”.

**Statement 3: "If I do seem to be becoming ill again I would like ..."**

Statement three produced responses that were coded and analysed thematically under the headings in Table 22.

More talking therapies	23 (29%)
More service input	23(29%)
Support to take medication	20 (25%)
Family and/ or social support	19 (24%)
Informal hospitalisation	18 (23%)
See my GP	17 (22%)
More and better communication with professionals	14 (18%)
Treatment in the community	10 (13%)
Better housing/ financial conditions	5 (6%)
See a lawyer	3 (4%)
Other	3 (4%)

**Table 22: Responses to preference for care statement 3: "If I do seem to be becoming ill again I would like:"**

One patient (P102) gave the following answer to statement three "If I do seem to be becoming ill again I would like ...": “*more support from the social worker and tenancy worker*”. Another one (P156) stated:

- “*proper communication with mental health professionals*”
- “*talking therapy*”

A third one (P53) wrote:

- “*to come into hospital informally*”
- “*an early outpatient appointment*”
- “*to discuss medication with the doctor*”

**Statement 4: "I would like you to contact ..."**

In response to statement four "I would like you to contact ..." just over half of the sample chose a member of their family while 48% chose a non-family member (Table 23). This may have service implications as almost 50% of the sample would chose non-family member which will be discussed in chapter 9.

<b>A family member</b>	41(52%)
<b>A non-family member</b>	
Other services (rehabilitation hostels, social worker, CPN)	10 (13%)
Friends	9 (11%)
GP	5 (6%)
Consultant psychiatrist	4 (5%)
Lawyer	2 (3%)
No-one	1 (1%)

**Table 23: Responses to preference for care statement 4:"I would like you to contact..."**

For example, one patient (P79) wrote: "my mother" and "my GP". Another (P107) wrote: "my father". A third one (P 15) wrote: "my husband".

### **Statement 5: "If I have to be admitted to hospital again I would not want ..."**

Six categories were identified under statement five "If I have to be admitted to hospital again I would not want ..." (Table 24). The majority of patients opposed the use of force (e.g. being handcuffed), coercion and intrusion during admissions and wished for their rights to be respected. They also stated that they would prefer to be admitted to hospital by psychiatric professionals who already knew them rather than the police or mental health staff that did not know them. Some patients also expressed their wish not to be treated with certain medication or injections (e.g. haloperidol, depot injections).

Force/ coercion/ intrusion	34 (43%)
Admission +/-by unknown staff	13 (16%)
Particular treatments	12 (15%)
Human rights not respected	6 (8%)
Others informed	5 (6%)
Unwanted contact from family	3 (4%)

**Table 24: Responses to preference for care statement 5:"If I have to be admitted to hospital again I would not want ..."**

For example, one patient (P1) wrote:

- *"I would not want the police to be involved unless absolutely necessary"*
- *"I would not want my employer contacted without my consent"*

Another patient (P11) stated:

- *"I would not want Haloperidol as I get bad side effects"*

A third one (P131) wrote:

- *"I would not want injections against my will"*
- *"Being placed on a locked ward"*
- *"Heavy-handed treatment"*

**Statements 6 and 7: "If I have to be admitted to hospital again I would want ....." and 7 "In hospital I would also like....",**

Statements 6 and 7 triggered responses such as better quality hospital facilities (e.g., 'my own room'), different types of treatment such as psychotherapy and counselling and respect of human rights (Table 25).

Better quality hospital facilities	34 (43%)
Treatments/therapies (e.g. alternative therapies, counselling, psychotherapy)	26 (33%)
Improved human rights	25 (32%)
More say/ explanations in treatment	11 (14%)
Avoidance of coercion	7 (9%)

**Table 25: Responses to preference for care statement 6 and 7: "If I have to be admitted to hospital again I would want ..."**

One patient (P150) wrote:

- *"In the ward round things to be discussed rather than me being interrogated"*
- *"My own room"*
- *"To receive regular counselling"*
- *"To have an independent advocate"*
- *"To know more about the decisions regarding my care and have a saying about these decisions"*

Another one (P145) stated:

- *"A room without traces of violence, without smoke fumes"*
- *"Provision of soap, shampoo and herbal teas"*
- *"To be sure my privacy as a woman is safeguarded"*
- *"Structural issues such as new light bulbs etc to be dealt with"*

In summary, patients' responses to the seven statements of the preference for care booklet fell into two categories. One category that mainly includes factors which lead to recurrent psychiatric episodes and hospitalisations and another category that includes factors patients identify as important to their treatment before and after hospitalisation. These findings and their implications will be discussed in the following chapter.

## Patients' follow-up questionnaire

Fifty-nine patients in the preference for care group were successfully followed-up a year after their discharge from hospital and provided views on the advance statement.

Do you remember drawing up a preference for care booklet?	Yes 44 (75%)      No 15 (25%)
Do you still have it?	Yes 27 (46%)      No 32 (54%)
Could you show it to me?	Yes 14 (24%)      No 32 (54%)
If No what happened?	Don't know 11 (19%) Lost it 10 (17%) Not on me /somewhere else 6 (10%) Other 7 (12%)*
Was it ever used in your care the last year?	Yes 2 (3%); No 35 (59%); Don't know 22 (37%)
If yes whose idea was to use it?	Key-worker 1 (1.7%); Consultant 1 (1.7%)
Was it helpful?	Yes 9 (15%)      No 24 (41%)
If Yes how?	Helped other people to understand that the patient is ill 3 (5%) Helped patient know when ill and needing admission 2 (3%) Reminded patient of things they can do to improve life 2 (3%) Helped with reality testing 1 (2%) Helped patient evaluate their illness 2 (3%)
If No why not?	Staff not aware of it /staff didn't produce it /refer to it 10 (17%) Didn't need it 7 (12%) Instruction was not acted upon 2 (3%) Other** 5 (8%)
Would you want to use it again?	Yes 24 (41%)      No 5 (8%)
Would you recommend it to other patients?	Yes 26 (44%)      No 2 (3%)
In what way do you think it could be improved?	9 (15%) recommended the following: Change design e.g. more like a bus pass to be carried around Staff should be more aware of it and use it Should be prominent in the medical notes Should have more clout Involve consultants /professionals more in it's its preparation Give more time to fill it in

**Table 26: Patients follow-up questionnaire**

Numbers are the actual number of consultants that gave each response. Where percentages add to less than 100% data were missing. \*Other: Left it in hospital; gave it to carer; not given to me; got destroyed; don't remember doing one \*\*Other: Was written when patient was not thinking clearly; forgot about it; design too bulky; lost it became out of date

The majority of patients (75%) remembered drawing up the booklet but more than half (54%) did not have it in their possession (see Table 26). The main reasons they gave for the latter included responses such as: “*I don’t know*”, “*I lost it*”, “*I don’t have it with me*”. Most of the patients reported that the preference for care booklet was not used in their care because they did not need it, because professionals were not aware of it or if they were, they did not produce it or refer to it during consultations with patients. Only two patients mentioned that the booklet was not useful because their instructions were not acted upon.

Only nine patients (15%) found the booklet useful because it helped them and other people around them to understand that they were ill and needed admission. Also, it reminded them of the things they could do to improve their ‘reality testing’ and their lives. Twenty four (41%) patients said they would like to use the booklet again and 26 (44%) would recommend it to other patients.

Finally, when we asked patients how could the advance statement be improved, they said that involving professionals in its preparation, changing the design (e.g. to look like bus pass), spending more time on filling it in and making it more influential, would be more useful.

## **Mental health professionals' views**

As mentioned in chapter 1, the preference for care study, also aimed to explore mental health professionals' views on the usefulness of psychiatric advance statements. The last part of this chapter will be focused on consultant psychiatrists' and patients' Care Programme Approach (CPA) key-workers views on the effectiveness of such documents.

### ***Consultant psychiatrists' responses to the follow-up questionnaire***

Consultants returned questionnaires on 31 (39%) of the 79 patients in the intervention arm (Table 27). Their responses to closed questions (such as "Do you remember if this patient had a preference for care booklet?") were counted and the actual number of responses is presented in Table 27. When open ended questions were asked (e.g. If Yes why?), their responses are presented either verbatim or coded into categories (see Table 27).

Do you remember if this patient had a preference for care booklet?	Yes 9 (29%)      No 22 (71%)
Did you ever see it?	Yes 8 (26%)      No 23 (74%)
Did you ever use it in the management of this patient?	Yes 3 (10%)      No 28 (90%)
Did you find it useful in the management of this patient?	Yes 5 (16%)      No 19 (61%)
If Yes why? 5 responses	"Her capacity to agree to treatment was relevant" "Interesting to discover what patients value most" "Allowed consultant to understand patient's experiences" "Basis of CPA" "Consultant routinely asks people about their early warning signs of stress"
If No why not? 26 responses	Patient did not want to use it" (2) Consultant prefers to talk face to face with the patient (3) "Consultant knew about what patient wrote anyway" (1) Unrealistic preferences given (5) Not integrated into the CPA (5) Not discussed with the patient (4) Consultant / team were not aware of it (14) Not applicable as patient was not in area (2)
How useful do you think this instrument is?	8 not useful at all 6 moderately useful 4 very useful
How do you think it would be improved?	"Redesigning of card (signs of stress not of illness)" 1 Integrate into system (CPA) 9 "Give indication that card has been done" 1 "Regular review of contents of booklet" 1 "Draw it up with the consultant" 1 "Have it in electronic format" 1
Would you want to use it again?	Yes 6 No 1

**Table 27: Consultant psychiatrists' responses to the follow-up questionnaire**

Numbers are the actual number of consultants that gave each response. Where percentages add to less than 100% data were missing.



Very few of them (n=9) remembered that the patient had an advance statement, saw it, used it or found it useful in the management of that patient. Five consultants who found it useful said that the booklet helped them to understand the patient's values and experiences and it was used as the basis for the Care Programme Approach meeting. Those who did not find it useful (n=19), gave a variety of reasons that ranged from: "*the patient did not want to use it*", "*unrealistic preferences given*", "*not integrated into the CPA*", and "*consultant/team were not aware of it*" (see Table 27).

The implications of the above findings will be discussed in the following chapter.

***Care Programme Approach key-workers' responses to follow-up questionnaire***

Care Programme Approach (CPA) key-workers returned the semi-structured questionnaire about the usefulness of the advance statement on only twelve of the 79 patients in the intervention arm (Table 28). Their responses to closed questions such as “Do you remember if this patient had a preference for care booklet?” were counted and the actual number of responses is presented in Table 10. When open ended questions were asked (e.g. If Yes why?), their responses are presented either verbatim or coded into categories (see Table 28).

Do you remember if this patient had a preference for care booklet?	Yes 4 (33%)      No 8 (67%)
Have you got it?	Yes 2 (17%)      No 10 (83%)
Can you access it easily?	Yes 3 (25%)      No 8 (67%)
If Yes how did you use it? 1 response	"As a basis talk about his hospital admissions to try and develop some insight into these and his illness. Unfortunately his preferences were quite unrealistic due to his lack of insight into how he gets ill."
If No why not? 9 responses	"Because some of the patient's requests are beyond my capacity and are colluding with his illness. The patient's perception is distorted by his mental disability so he is asking to be respected when he is meaning to have done exactly what he wants." (1) "I can't remember if I gave it to the patient or not." (1) Don't remember seeing it or I am afraid I am not aware of this booklet. (6) "He was transferred to another sector on his discharge. I did not have the opportunity to deal with this matter." (1)
How useful do you think this instrument is?	4 (33%) not useful at all 1 (8%) moderately useful 7 (58%) don't know
How do you think it would be improved?	"It is very difficult with psychiatric patients due to the distortions of perception." 1 "Key workers to be involved in this initiation at the very beginning." 1 "If it could be updated after every admission and used ongoingly." 1 "The booklet is fragile. It needs to be more durable." 1
Would you want to use it again?	Yes 3 No 8

**Table 28: CPA key-workers responses to the follow-up questionnaire**

Numbers are the actual number of consultants that gave each response. Where percentages add to less than 100% data were missing.

Similarly to consultant psychiatrists, very few CPA key-workers remembered that the patient had an advance statement or found it useful. They also reported that they did not have a copy of it that could be accessed easily. An example of how one CPA key-worker used the advance statement was: *“as a basis to talk about the patient’s hospital admissions and helped him develop some insight into these and his illness. Unfortunately, his preferences were quite unrealistic due to his lack of insight into how he gets ill”* (see Table 28).

Most CPA key-workers reported they did not use the booklet mainly because they were not aware of it, the patient’s preferences colluded with his illness or the patient was transferred to another sector.

When CPA key-workers were asked about how the advance statement could be improved, they said it should be made more durable, that they should be involved in its design and drafting, it should be reviewed regularly and probably be used with a different psychiatric population.

The implications of the above findings will be discussed in the following chapter.

## **Chapter summary**

This chapter focused on the findings of the preference for care booklets and the participants' and professionals' views on the usefulness of the booklet. In summary, patients presented their views in relation to signs of lapses and relapses, and their preferences and refusals on certain aspects of their treatment and needs whilst hospitalised. A proportion of them also stated they valued the booklet. There was a consensus of views among consultant psychiatrists' and Care Programme Approach key-workers to the follow-up questionnaire. Despite the fact that copies of the advance statements were placed at the front of patients' hospital notes and sent to consultant psychiatrists and Care Programme Approach key-workers, very few of them remembered or saw or found the booklets useful. Contrary to patients' views and expectations, some of the professionals thought the patients' preferences for care were unrealistic. In the next chapter, the implications of the findings of the preference for care study will be discussed.

## **PART IV**

### **DISCUSSION**

#### **CHAPTER 9**

##### **Aims of the study**

The preference for care study is a pragmatic, randomised controlled trial that aimed to evaluate:

- Whether the use of advance statements by sectioned patients who are near discharge from section, leads to lower rates of compulsory readmission to hospital.
- Whether patients who have completed psychiatric advance statements report higher self-efficacy.
- Whether patients who have completed psychiatric advance statements report higher satisfaction with psychiatric services.

In this chapter, I will discuss the results of the study against the hypotheses I set out to test, the methodological limitations of the preference for care study within the context of similar theoretical and empirical evidence, the impact of psychiatric advance statements for sectioned patients within the current legal guidelines and future evaluations of such documents.

## **Summary of results in relation to main hypotheses**

*Hypothesis 1:* sectioned patients' advance statements for psychiatric treatment, when disseminated in written form to key-workers and general practitioners and included in patients' case records will reduce the frequency of compulsory re-admissions to hospital.

The first hypothesis is rejected because users' advance instruction directives had no impact on the rates of compulsory re-admission during the 12 months of follow-up. The same finding applied for number of days spent on subsequent sections, days as an in-patient on a subsequent voluntary admission or number of patients re-admitted voluntarily.

*Hypothesis 2:* Sectioned patients who have completed advance statements for psychiatric treatment will report higher self-efficacy than patients who have not. No significant difference was found in self-efficacy scores between the experimental and control group at follow-up which led to rejection of the second hypothesis

*Hypothesis 3:* sectioned patients who have completed advance statements for treatment will report higher satisfaction with psychiatric services than patients who have not. The third hypothesis was also rejected because there were no significant differences in satisfaction with services at follow-up.

## **Summary of results in relation to predictors of outcomes**

Two variables were important in predicting subsequent sectioned admissions: the number of previous admissions and household composition. It appeared that two or more previous admissions increased the odds of re-admission to almost two and a half times that of someone who had one or no previous admissions. Also, someone who lived alone was approximately twice as likely to be re-admitted as someone who lived with a partner, parent or other.

## **Summary of results in relation to other outcomes**

There were no significant differences between the intervention and control groups in terms of baseline characteristics concerning hospital care (time spent in hospital the year before the index admission and the number of admissions in the previous five years). However, patients in the advance statement group spent less time in hospital during the index admission than those in the control group.

Mental health status at baseline, as assessed by the BASIS-32 and HoNOS, did not differ significantly between the two groups. However, patients in both groups reported fewer symptoms of mental illness at baseline and more symptoms of mental illness at follow-up. There was no indication on other parameters that the patients' clinical state had deteriorated by the time of follow-up.

## **Summary of findings from the Preference for Care booklet and the patients' and professionals' views on the usefulness of the booklet**

The content of the preference for care booklet revealed that sectioned patients were able to draw up advance statements similar to those of other populations with mental health problems (18;25;85;92). The psychiatric advance statements of this study, contained statements on first signs of relapse, statements about what should be done at the first sign of relapse, who to contact at the time of relapse, advance refusals of specific treatments and treatment preferences. Sectioned patients did not use the directives as an opportunity to refuse all treatment. Instead, they refused certain prescribed medication due to side effects (e.g. haloperidol), and expressed their wishes against use of force, coercion and intrusion before they became hospitalised and during hospitalisation.

Three-quarters of patients at follow-up remembered having drawn up an advance statement but only a small percentage of those found it useful. The ones who found it useful reported that it was used as a 'reality-check' to help them evaluate their condition, or as a way of seeking care and engaging themselves in activities that might improve their condition and quality of life.



In only five instances did the psychiatric consultants who returned questionnaires find the directives useful in increasing their understanding of their patients' values and subjective experiences and serving as a tool for patients' empowerment. Overall, Care Programme Approach key-workers, did not find the advance statement useful. Consultant psychiatrists and Care Programme Approach key-workers who were aware of the booklet still did not find it useful. They claimed that it was not integrated into the patient's care plan or they were not involved in the process of drawing up the booklet. Some consultants and care programme approach key-workers believed that patients would have impractical preferences. The data from patients suggested desire for reasonable and relatively small changes such as better quality hospital facilities (e.g. "*A room without traces of violence*", "*My own room*"). However, within the limited resources of the service these requests might still be impossible to meet.

## **Methodological limitations**

### ***Recruitment***

Six hundred and five in-patients were assessed for eligibility during baseline. Of those, 372 did not meet inclusion criteria, 27 refused to participate and 45 were discharged too early or without notice. Although this is a large number of excluded participants, it is not unusual in this type of research. Psychiatric patients are considered one of the most difficult groups of the population to do research with (29;75;149;159). Although the exclusion criteria were kept to a minimum, a large number of psychiatric patients, mainly at St Ann's hospital, were people from ethnic minorities who were unable to read and write English.

Other reasons for excluding some of the 372 patients were lack of mental capacity, presence of organic and psychoactive substance use disorders and those on other specialised sections of the Mental Health Act 1983. Significantly more male than female patients participated in this study which is a characteristic of the sectioned population in this country (160) .

Only 27 (6%) eligible participants refused to participate in the study. This is a low figure and indicates that either the majority of patients were genuinely interested in the study or were eager to comply with any professional who approached them before they were discharged. My impression was that they were genuinely interested in the study and is supported by the fact that more than 70% of them accepted to be interviewed at follow-up.

Some may argue that considering sections 2, 3 and 4 of the Mental Health Act (1983) together meant that this study recruited a heterogeneous population. Although there are no official statistics that give detailed profiles of the different individuals on these three sections, I believe that the three sections target similar individuals. Sections 2, 3 and 4 come under Part II of the Mental Health Act (1983) and aim to protect the health and safety of individuals who suffer from a mental health problem and those of the society in which they live. According to government statistics for the period of the study, the majority of patients on section 4 were transferred to either section 2 or 3, and the majority of people in

sections 2 and 3 were changed to informal (160). This suggests that individuals in the three groups were not different in terms of the course of their mental health illness. In addition, statistical analyses showed that patients were evenly distributed by type of section at the baseline of the study suggesting that basis for admission had no biasing influence on the representatives of the sample.

The recruitment of sectioned patients in this study could possibly limit the generalisability and usefulness of the results to the general psychiatric population which includes voluntary psychiatric patients and those cared for by community based psychiatric teams. The study aimed to evaluate the effectiveness of psychiatric advance statements for sectioned patients because the autonomy and self-determination of this particular group of psychiatric patients are especially limited. The design of a pragmatic randomised controlled study such as the present one could only target one group of the psychiatric population. Of course a different study design could have included several groups but would have been more expensive to run.

### ***Randomisation***

The present study was a pragmatic, between groups, randomised controlled trial. These trials aim to evaluate an intervention (in this case the effectiveness of psychiatric advance statements) in everyday clinical practice. The strength of this randomised study lies in its design and consequently the elimination of allocation bias or risk of confounding. No obvious differences in characteristics between the two groups at baseline assessment were detected, suggesting that randomisation had minimised bias.

However, some may argue that the study was still subject to biases. These may have involved patients' preferences, lack of blinding of investigator being recruited for the study and non-random losses of participants at follow-up. Patients did not express strong preferences in this study and seemed to understand my explanation that the effectiveness of psychiatric advance statements had not been tested so that two groups needed to be compared to find out if psychiatric advance statements would make any difference to readmission rates. Another explanation for the participants' compliance may be the time at which I recruited the patients. Patients near discharge from section, and in most cases from hospital, were very eager to leave the hospital and may have been more likely to comply with professionals' requirements. Although I was not part of the clinical teams and the participants were aware of that, they may have felt compelled to comply. However, I attempted to remove this potential bias by use of an information sheet and by verbal explanation making it clear that their refusal to participate would not affect their care in any way. Yet another explanation may be the participants' lack of deeper understanding of the issues involved in the process of giving informed consent or of the purpose of the trial. Although the informed consent letter and the summary of the study explained very clearly and simply the randomisation process this particular sample may lack the cognitive abilities necessary to process this type of information. One solution would have been to add a test to check their understanding. This was not done as would have been very time consuming and impractical in an already long interview process. The feasibility study suggested that increase in the length of interview would be difficult for patients. However, a full pilot study (limited by time and financial constraints) was not carried out.

Furthermore, the possibility that the patients did not completely understand what they were being asked to do may have contributed to the lack of detectable differences between groups at final analysis.

As I previously mentioned in the methods section, blinding of the participants was impossible in this study as they had to write down their preferences for care. Blinding of the researchers was also impossible as I was required to assist the participants to complete the preference for care booklet. Outcome assessments however, could have been done by someone else blind to the experimental and control groups. A different type of design would have been required in order to blind the researchers. For example, a researcher could have approached participants and obtained informed consent, then an independent interviewer such as a patients' advocate could have randomised and helped patients to complete the booklets while yet another researcher could have collected, recorded and analysed the data. However, since the primary outcome was an objective measure which could not be influenced by the researcher, blinding did not seem essential. This would in any case have been beyond the resources available for the study.

A final argument against the validity of this study might be the non-random losses of participants at follow-up. However, the primary outcome (re-admission rates) of this trial was not subject to the constraints of missing data. It is unlikely that such biases applied to the secondary outcome measures such as BASIS-32 and hospital satisfaction because firstly the follow-up rate was particularly high for this population (75% of the experimental and 71% for the control) and secondly statistical analyses between completers and non-completers did not show any significant differences in baseline characteristics between the two groups. The only statistically significant difference between non-completers was found in satisfaction with services. Non-completers in the preference for care group were more satisfied with services at baseline. Purely by chance the randomisation process could lead to this imbalance. Another interpretation could be that those who were satisfied with the services that they received in hospital decided that it was not worth continuing with the study. Other interpretations could be that they could be a more passive group with less interest in being involved or they were just happy to leave it to professionals.

### ***Power of the study***

Although, hospital data of sectioned admissions in the previous year were used to calculate the sample size, fewer patients than expected (about 10% fewer) were compulsorily readmitted in both arms of the trial. This led to lower statistical power than predicted. However, the difference between trial arms in proportions of patients readmitted under section was so small that inadequate power is unlikely to be an explanation. Although this drop may simply reflect a secular trend in the trial area, it runs counter to the increased number of involuntary admissions in England from 23,725 in 1996-1997, to 25,415 in 1997-1998 (160). This could be a classic Hawthorne effect. Professionals in both arms of the trial may have modified their behaviour in response to being observed in a trial that concerned patients' preferences and subsequent rehospitalisation. Professionals would have had to be unaware of the trial which was not feasible as I had to obtain their opinion about patients' competence and their permission to approach patients. Finally, there is a possibility that figures for readmissions during the period were unusually high.

### *Choice of outcome measures*

One of the limitations of this study is the concentration on distal outcome such as compulsory re-admission instead of proximal outcomes in the process of care. Psychiatric advance statements as a form of anticipatory planning for future treatment may exert some beneficial effect on therapeutic alliance, communication and continuity in community-based treatment before they affect distal outcomes. The benefit of choosing services data for evaluation of primary outcomes lies in two premises:

- It is readily available for all participants.
- It is not affected by drop out rates from research follow-ups.

However, as this study has shown, the interpretation of such data may be difficult. Was the rate of compulsory re-admission lower because professionals already took account of their patients' preferences or because patients were clinically improved for other reasons (e.g. intense community-based treatment)? If patients were clinically improved why did they report more symptoms on Basis-32 at follow-up in comparison to the baseline? One might argue that near discharge patients had less insight into their problems (or were concerned to present themselves as being well) than one year later, when they reported their difficulties more frankly. The absence of other signs of clinical deterioration would add extra support to that argument. To resolve the problem of interpreting distal outcomes the addition of proximal measures of outcome would have been helpful. These could have involved observational methods and/or videotaping of clinical consultations (e.g. to evaluate therapeutic alliance and communication), interviews and questionnaires.

Another limitation of this study is the use of the generalised self-efficacy scale at follow-up. Although research has shown that post-treatment rather than pre-treatment self-efficacy is a better predictor of reporting higher self-efficacy (in other words reporting increased confidence in achieving aims such as managing one's own mental health and voluntarily admitting oneself to hospital), it would be more informative for the study of this population to have a baseline comparison (130;146). In addition, future studies should incorporate Pearlman et al's (1995) model that takes into account the multiple psychological processes that underlie

psychiatric advance planning (141). As mentioned in chapter 3, complex interventions such as the implementation of psychiatric advance statements require detailed planning and assessment of the participants' psychological motivators and coping mechanisms. Similar measures are needed in other health promotion activities (e.g. smoking cessation and weight loss) to study factors that will facilitate or hinder the uptake, design, implementation and revocation of such documents. Unfortunately, the time scale and funding for the preference for care study did not allow for such interventions.

#### ***Choice of the listwise or casewise approach for missing cases***

For missing cases the listwise or casewise approach was used which means excluding the whole case from the analysis. The remaining samples may be not a fair reflection of the population from which they were presumably drawn. The limitations of this approach are that the low sample sizes lead to lower power and the possibility of type II error. However, as mentioned above, the primary outcome measure of the study was not affected by this approach because we were able to obtain information on 100% of the participants from their case notes.



### ***Predictors of outcome and detention under the Mental Health Act 1983***

Although the number of psychiatric beds decreased during the 1990s in England and Wales, the number of sectioned admissions under Part II of the Mental Health Act 1983 almost doubled (160). What are the causes of this paradox? A number of different hypotheses appear in the literature that include the following (195):

- Pressure to release psychiatric beds may lead to premature discharges from hospital consequently increasing the likelihood of re-admission under a section of the Mental Health Act.
- Lack of psychiatric beds may lead to delay of patients' admissions to the point where their deterioration requires admission under the Mental Health Act.
- Due to lack of psychiatric beds mental health professionals may have become more conscious about the safety of the patients and the public, especially, after publicised scandals of homicides committed by people with mental health problems.

An important finding of the present study was that participants with two or more previous admissions were almost two and a half times more likely to be re-admitted under section than those with one or no previous admissions. The above hypotheses could explain this finding.

Another significant change in the official figures for sectioned admissions between 1988-1999, which was also apparent in this trial, was the increase in detentions of male patients. The Office for National Statistics for England and Wales (2002), has reported that this trend might be due to the effect of 1980s recession that drove more men than women to unemployment (160). An increase in one-person households (that has been among men under the age of 65) and male actual or attempted suicide rates may be another underlying factor of these changes in the Act. In the present study statistical analysis showed, that someone who lived alone was approximately twice as likely to be re-admitted as someone who lived with a partner, parent or other. This finding is in accordance with the above trends and might be explained by social changes in the last decade.

More specific targeting of particular groups might lead to increased usefulness of psychiatric advance statements.

### *Assessment of mental capacity*

A formal test of assessment of sectioned patients' mental capacity was not part of the study because one of the inclusion criteria for the study was competent adults of 18 years and over. Clinicians indicated to me patients that they considered to be competent before I approached any participant. I relied on this opinion and my own assessment that the patients understood the process and content of the interview and they were able to weigh the pros and cons of participation in the trial by re-stating in their own words their understanding of the concepts and the processes involved. Although this may be a limitation of the study, I do not believe it undermines its validity because clinicians always determine the competence of the sectioned population in the first place. According to the clinical teams at St Ann's and the Royal Free hospitals, a significant proportion of sectioned patients, especially those with the most chronic illness, were not competent to participate in the study. The reasons for exclusion included the patients' impaired cognitive abilities to understand, retain, believe and weigh evidence in relation to their treatment and arrive at informed choices. Clinicians who worked closely with these patients gave me a number of examples relating to the above functions. Of the patients they referred to the study, only six were not able to comprehend the information presented to them thus excluded from the study. I therefore considered the clinicians assessment to be adequate to satisfy the inclusion criteria.

However, I believe that future research should incorporate a formal assessment of competence. Research evidence has shown that the most appropriate instrument to date for the evaluation of mental capacity is the MacArthur Competence Assessment Tool for Treatment Decisions (MacCAT-T) which assesses abilities related to each of the four legal standards for mental capacity. This instrument is valid and reliable and requires 15-20min to administer (114). The most important advantage of using a scale such as MacCAT-T for research purposes, is to clarify decisions about competence in borderline situations. Using the scale will ensure that researchers have covered the full range of abilities that should be considered in making competence judgements, it will provide documentation of the researchers' care in informed consent disclosure and inquiry, it will help structure

the researchers' reasoning about mental capacity, and it will equip researchers with evidence they could use to explain to third parties how the final judgement was made. Use of scales also ensures studies are comparable. The disadvantage of using a mental capacity test in studies like ours is that they will prolong an already lengthy interview process which may discourage patients from continuing in the study.

## **Effect of the booklet**

The decision that the patients should prepare the psychiatric advance statements outside the Care Programme Approach meetings was based on three main factors:

- The limited time and expertise of clinicians in issues of advance care planning,
- The belief that mental health professionals outside the patient's team would be unbiased and more likely to advocate the patient's rights and preferences.
- The unclear legal status of psychiatric advance statements in this country at the time the study began.

The first factor was made clear to our research team during the meetings we had with the mental health teams at the two hospitals. Early research findings in studies of the medical advance statements suggested the second factor might be relevant (53;64). However, our study suggests that developing the psychiatric advance statement outside these meetings and placing the record at the front of the hospital notes may not be the most appropriate way to evaluate the effectiveness of such instruments. Some may argue that filling out a piece of paper will not work unless the treating team is involved. This was not the case in this study because I and the other researcher went to great lengths (e.g. talking to nurses and psychiatrists both face-to-face and on the phone about the advance statement) to make sure that the treating team was aware of the patients' preference for care booklet. We also sent copies of the booklet to all parties responsible for the patient's care. Our findings are supported by the Bradford Advance Statement project that involved a considerable amount of developmental work with mental health professionals and service users for the advance statements to be implemented (29;75;196). Despite the extensive developmental work, the Bradford Advance Statement project also failed to develop a model of good practice for the use of psychiatric advance statements because advance statements were not incorporated into existing Trust policy. As the authors suggest, "due to the current legal status of advance statements, accountability for the inclusion of a statement in decisions made about an individual's care and treatment would ideally come from within Trust policy. This would involve the acceptance of advance statements as a useful tool of communication between service users and service providers."(29) (p.3) Greater involvement of professionals and patients in the emerging design of any future studies would be essential.

A further reason that might have contributed to the lack of awareness of the advance statement in this study, was that the participating psychiatric units suffered the lack of resources typical of inner-city areas and the professionals were struggling to cope with the administration of the Care Programme Approach, which formalises the process of community psychiatric care in England and Wales. Frequent changes of key-worker might also have led to confusion about the purpose of the statements or the ignorance of their existence which the professionals' views revealed. Key-workers in one psychiatric service were often not allocated before patients were discharged, which might also have reduced the impact of the booklets. Moreover, the advance statement was sometimes regarded as an administrative burden by staff, who assumed that their management already took into account of patients' wishes. These difficulties, however, are not uncommon features of psychiatric services in large metropolitan areas, and are an expected part of any realistic setting in which advance statements would be implemented.

Another reason for the lack of incorporation of the psychiatric advance statements into the clinical work of the mental health professionals might be that they considered that they had already incorporated patients' views adequately. Future studies, could test these claims by asking mental health professionals to guess patients' preferences for treatment and comparing them with actual ones. However, data from studies in general medicine have shown that primary and secondary care clinicians were not accurate in predicting their patients' treatment or non-treatment preferences (70;71).

Unfortunately, however, use of the Mental Health Act may make sectioned patients in the study group fearful and suspicious of service personnel. Agreeing advance statements with their own mental health professionals may mean that they feel unable to be frank about their care with those who deliver it. In this study, the advance statement was therefore drawn up with someone independent of the patient's care. To achieve such independence in routine settings, a patient advocate might be involved. Due to limited funding of this study, this could not be

incorporated. However, this could risk diminishing the treating professionals' sense of 'ownership', or commitment to honour the terms of the statement and might have an effect on distal outcome measures such as patient re-admissions. The latter and the confusing legal guidelines for the implementation of such instruments in this country minimise any effect interventions such as the preference for care study may have. As the only successful study in this area has shown, for advance statements to be successfully implemented, they have to be incorporated into existing Trust policy and formulated jointly by the patient and his/her mental health team (e.g. care co-ordinator, psychiatrist and project worker) (19).

## **Findings from the Preference for Care booklets**

### ***Limitations of content analysis***

Although the advance statements had no impact on subsequent compulsory and voluntary admissions to hospital, content analysis of the data provided a rich source of information about sectioned patients' views on first signs of relapse, their preferences for care and advance refusals of specific treatments if they became ill again, who to contact if they relapsed, and specific preferences if relapse could not be prevented and they became hospitalised again. One limitation related to the content analysis of the preference for care booklets surrounds the development of the codes/themes under the different statements of the booklet. One could argue that the researchers' background in psychology and psychiatry may have contaminated the data in that we developed categories that 'squeezed' the data into pre-defined categories similar to those in the diagnostic manuals in psychiatry instead of allowing the categories to emerge from the data (191-194). For example, when a patient made a reference of "I notice I am becoming ill again when I hear voices", both researchers created the code/theme of 'Positive psychotic symptoms'. A researcher with a different academic and professional background may have provided a code/theme. However, the funding for the preference for care study did not allow for the employment of another researcher who could undertake that responsibility. Future studies could explore this area further.

Another limitation of the content analysis of this study refers to lack of triangulation because the nature of the study did not allow for respondent validation (191).

### ***The findings on signs of relapse***

Answers to the first two statements of the preference for care booklet showed very clearly that sectioned patients had adequate insight and understanding into the precipitating factors of their lapses and relapses. According to their statements, precipitating factors included exacerbation of their psychiatric symptoms (e.g. positive and/or negative psychotic symptoms), non-compliance with medication,

use of alcohol and drugs, relationship problems and social, financial and work problems. None of the few existing studies on the content of advance statements has reported what psychiatric patients' first signs of relapse are which makes comparison of our findings difficult (18;25;85;92). However, the precipitating factors cited by our sample are within the range of expected signs of relapse for that group of psychiatric patients.

### ***The findings on patients' preferences for care if they relapsed and were admitted to hospital again***

The core preferences of patients included more talking therapies, more service input, support to take their medication, family and social support, informal hospital admissions and treatment in the community, increased and better communication with mental health professionals. When the patients were asked to express their preferences for care in case they were re-admitted to hospital they requested better hospital facilities (e.g. "a room without traces of violence"), alternative therapies, avoidance of coercion, improved human rights, more say and explanations in treatments. Our findings are in accordance to those of similar studies (25;85;92). Amering et al's (2005) study suggested, that "much thought was given to ensuring that the advance directives were feasible and that preferences fell reasonably within the range of options of the mental health system." (85) (p. 249) The preference for care study also supports this finding.

However, as mentioned in chapter 1, advance preferences for psychiatric care no matter how reasonable and feasible they may appear to be, don't have any legal weight under the new Mental Capacity Act 2005 or the report of the expert committee on the review of the Mental Health Act 1983 (27;28). As the preference for care study and the Bradford advance statements project have shown, the legal situation in this country influences the validity of designing and implementing such documents outside existing Trust policies (29;31).

### ***The findings on patients' refusals***

As previous studies on other psychiatric populations suggested, sectioned patients did not use the advance statements as an opportunity to refuse all treatment as is



popularly supposed by their critics (18;25;85;92). This is an important finding that suggests that psychiatric advance statements could be used to evaluate patients' choice and compliance with different forms of treatment.

The majority of our patients expressed their opposition to use of force/coercion/intrusion. One patient wrote: "I wouldn't want to be handled by the police or handcuffed". Another one wrote: "I wouldn't want people to force me with their strength to take medication". Patients also reported that they wouldn't want particular treatments (mainly Haloperidol and depot injections due to their side-effects) and to be admitted to hospital by unknown staff. A few patients also reported boundary rules (e.g. unwanted contact from certain family members and others to be informed about their illness). These findings are also in accordance to those of similar studies (18;25;85;92).

Similarly to advance preferences for psychiatric care, advance refusals for psychiatric care are not legally binding in this country (27;28). As the draft code of practice for the Mental Capacity Act 2005 suggests, treatment for mental disorder could be given under the Mental Health Act 1983 without the patient's consent "and even where the patient is making or has made a decision to refuse a particular treatment for that particular condition."(30) (p. 91) In contrast to the USA, where a few states have legally recognised the validity of advance refusals for psychiatric treatment for a certain period of time (up to 45 days) before treatment could be given under the Mental Health Act, in the UK the current legislation still undermines psychiatric patients' autonomy and self-determination by preventing them their right to exercise their wishes (33).

### ***The findings on patients' preferences to contact another individual in case they relapsed***

In response to the statement "I would like you to contact...", 52% of patients asked for one or more family members to be contacted. In addition, 48% of patients asked for certain friends and certain professionals involved in their care to be contacted (e.g. GP, consultant psychiatrist, lawyer, social worker and CPN). Only one patient stated that no-one must be contacted. These findings are also supported by those of similar studies (18;25;85;92). These findings could be

useful for the treating teams who could focus on interventions that would strengthen the patients' existing relationships. Furthermore, statistical analyses of the predictors of outcome in chapter 7, showed that patients who lived alone were twice as likely to be re-admitted as someone who had a different household composition. Psychiatric advance statements could be used as means of identifying or even providing a proxy decision maker for the patient who could in turn monitor the management of their illness. Such a proxy decision maker could obviously influence social support systems too.

In summary, the content of the patients' advance statements in the preference for care study was very similar to that reported in other studies. Sectioned patients showed adequate insight and understanding into the precipitating factors of their lapses and relapses and chose feasible and reasonable treatment preferences. In addition, they did not use the advance statements to refuse all psychiatric treatment, undermining a common criticism of the opponents of implementation of such documents.

## **Patients' views**

Three-quarters of the patients at follow-up remembered that they had drawn up an advance statement. However, over half of them either did not remember what had become of it or had lost it. This suggests a lack of understanding of the importance of the instrument or a lack of affirmation of the booklet by staff (see below). The short feasibility phase of the preference for care study showed that the interview process was already long enough. To add another long structured instrument that would test the patients' understanding of all the concepts would make the interview process unmanageable by the patient within the context of this study. In addition, myself and the other researcher used our professional judgement to test the patients' understanding by asking the patient to re-state in their own words what they understood when there were cues that the patient was uncertain about certain concepts and procedures. However, a different study design such as a qualitative interview could incorporate a test to check patients' understanding of psychiatric advance statements and of randomised controlled trials such as this one.

A small percentage of patients found advance statements useful mainly as a 'reality check' to help them evaluate their condition, or as a way of seeking care and engaging themselves in activities that improved their condition and, as a consequence, their quality of life. Three patients also mentioned the usefulness of the booklet as a means for improving communication with 'important others'. These factors demonstrate the potential therapeutic value of psychiatric advance statements in the promotion of patients' self-determination in, and planning for, a time of anticipated incapacity.

Why did over 40% of our sample not find the advance statements useful? As the patients suggested this may have occurred because the professionals involved in their care did not refer to it or take account of it. As the study by Henderson et al (2004) showed, joint crisis plans that are developed by the patient and his/her mental health team have the potential to reduce compulsory admissions and increase compliance with treatment for severe mental illness (19). In addition,

educational interventions tailored at improving psychiatric staff awareness, involvement of service providers in development of advance statements and ensuring that the various treatment providers (e.g. outpatient, inpatient, emergency and crisis services) are aware of them may influence the effectiveness of such instruments. Education, legal aid and clear, concise training material would also help patients to construct effective and useful psychiatric advance statements. Research findings regarding medical advance statements suggested that counselling by hospital patient representatives improved recognition and execution of the statements in acute medical wards (64). Brown et al (1999) have shown that mailing of written materials to participants increased placement of an advance statement in patients' medical records substantially (65).

Furthermore, when the patients were asked if they would want to use the booklet again and if they would recommend it to other patients the majority of them said yes. This finding is in accordance to other findings reported by similar studies and may be interpreted as a genuine belief in the usefulness of such documents or a bias on the part of the patient to please the researcher (18;25;92). Future studies could incorporate an in-depth interview to explore this area further.

When the patients were asked about the ways in which the advance statement could be improved they suggested that a smaller size (e.g. like a bus pass) could be easier to carry around and more time to fill it in would help them to personalise the booklet. Both of these recommendations have been made by other psychiatric patients in other studies and could be used as a guide for future research (18;85;92). Some patients also suggested that if the booklet had more clout it could be more effective. However, lack of clarity surrounding the legal status of advance statements when the preference for care study began, undermined the importance of the booklet in the patients' care. Even within the current legal guidelines (e.g. the report of the expert committee on the review of the Mental Health Act 1983 and the Mental Capacity Act) implementation of advance statements would be problematic. Although these statements are recommended as part of good clinical practice, the final responsibility for their implementation is placed on the different Mental Health Trusts without the provision of clear guidance as how to implement them (27;28;30).

Finally, two patients reported that their instructions were not honoured and seven said they did not need to invoke them because they did not have a relapse. As other studies have reported, not honouring the patients preferences can undermine both the trust of the patients in the study and their confidence and trust in their clinical team (18;25).

## **Professionals' views**

The response rate of mental health professionals to the follow-up questionnaire on the usefulness of psychiatric advance statements was very low. As a result the generalisability of our findings is limited.

In only five instances did the psychiatric consultants who returned questionnaires find the advance statement useful for the patient's care by increasing their understanding of the patients' values and subjective experiences and serving as a tool for patients' empowerment.

Some mental health professionals believed that the patients would have given unrealistic preferences, something that does not fit with our data from patients. Only one mental health professional explained what they meant by unrealistic preferences (e.g. "unfortunately his preferences were quite unrealistic due to his lack of insight into how he gets ill"). In hindsight, an in-depth interview to identify what the consultants and key-workers meant by unrealistic preferences would be more useful than just a semi-structured questionnaire. Unfortunately, the funding and design of the preference for care study did not allow for more in depth qualitative work to be undertaken. Future studies could incorporate that element.

The majority of consultants who returned questionnaires did not find the booklet useful in the management of the patients often because they claimed that they were not aware of its existence, despite the fact that the booklets were displayed prominently at the front of each patient's case-notes throughout the study. I and the other researcher identified the booklets at the front of the case-notes during the follow-up phase, a year after the patients' discharge. Many of those who were aware of the booklet still did not find it useful, claiming that it was not integrated into the patient's care plan or they were not involved in the process of drawing up the booklet. Although in keeping with other published accounts of use of advance statements (53;66), it is surprising that briefing of health professionals about the statements, sending a copy for each patient to them and placing a further copy at the front of the medical notes, did not increase their awareness of the existence and possible usefulness of the booklets. A consensus approach to the development of such instruments prior to any study (e.g. pre-clinical justification for the

intervention and modelling-defining the intervention and understanding the relationships between the component parts) might provide a more fertile ground for the successful implementation of the advance statements. Unfortunately the funding of the preference for care study did not allow for such an extensive work to take place before the study began. However, as the Bradford advance statement project has shown, involving professionals and extensive education of patients still failed to enthuse their service users to take up the use of advance statements (29;75). As Thomas (2004) wrote, “this implies a more fundamental problem relating to power and powerlessness. Psychiatry, unlike any other branch of medicine, is the only specialty in which treatment is regularly given for extended periods against the person’s wishes. Many service users do not consider themselves ill, yet find themselves forced to take medication. Another way of understanding the reluctance of service users to plan ahead is that they feel demoralised, disempowered, and oppressed by years of compulsion in the mental health system. We must be circumspect in hoping that interventions such as advance statements will change the situation. Psychiatrists are not the only oppressors; we include here the panoply of state control of deviance, stigmatisation by society, and our collective social intolerance of difference.” (75)(p. 123)

Successful implementation of advance statements as Henderson et al (2004) have shown requires a culture change and a more collaborative way of working with psychiatric patients (18;19). Joint crisis cards and advance agreements may be the way forward. However, more studies are needed to confirm that Henderson et al’s (2004) results can be replicated in other locations and different settings and preferably with patients leading the process of implementation rather than mental health professionals. In addition, as Srebnik and Brodoff (2003) have suggested, a computerised form of the patients’ statements that would be available to mental health professionals 24 hours a day and specific training to staff on implementation issues before they are faced with such documents might help the psychiatric staff to comply with it (87).

## Summary of methodological issues

This study has increased our understanding of the design and implementation of psychiatric advance statements. I realise however, that it could have increased our knowledge even further, if certain factors had been incorporated in the study's design. These could be summarised as follows:

- A pilot phase that would justify and model the intervention.
- A different sample of the psychiatric population and a different study design (e.g. a cluster randomised controlled trial with inpatients under the care of community mental health teams and assertive outreach teams).
- Choice of proximal outcomes (e.g. therapeutic alliance, compliance with treatment, strengthened relationships) rather than distal outcomes.
- An assessment of competence for making, applying and revoking the directives.
- An assessment of the patients' understanding of the importance of psychiatric advance statements.
- A pre-and-post-treatment evaluation of specific self-efficacy beliefs and the implementation of a more complex psychological model that would take into account the whole process of advance care planning rather than the end product of it which is the design and implementation of advance statements.
- Incorporation of the advance statements within the Mental Health Trust's policy.
- Involvement of patients' mental health professionals and advocates in the execution and implementation of such instruments.



## **Future directions of research**

The preference for care study has shown that the design of psychiatric advance statements by sectioned patients before they are discharged from section with the help of an independent mental health researcher does not have any impact on future voluntary or involuntary admissions. Throughout this discussion, I have considered how future evaluations could be modified in order to maximise the chances of success when undertaking studies in this area in the future. In summary, the only successful trial on implementation of such documents so far by Henderson et al (2004) showed that future studies should incorporate and research different types and forms of advance statements such as joint crisis cards and advance agreements (19). However, it is not clear from Henderson et al's (2004) study who had control of the process of selection and initiation of joint crisis cards (e.g. service users or research staff?) and what training, preparation and development work took place with users and staff (19). Future studies should explore these areas further. In addition, future studies should explore integration of the advance statements into existing Mental Health Trusts' policies in different geographical locations in the UK (e.g. inner city versus rural areas) and with different patient groups (e.g. early intervention services versus long term psychiatric facilities). Finally, there should be more qualitative assessments of both mental health professionals and psychiatric patients before and after future trials that involve implementation of psychiatric advance statements. Qualitative data could be gathered during in-depth interviewing in order to identify the issues that are involved in the processes that facilitate and/or hinder the design and successful implementation of advance statements.

## Chapter 10

### Conclusions

Advance statements for psychiatric care, as implemented in this study, had little impact on subsequent admission to hospital or on other secondary outcomes such as clinical and social status. In addition, the data that was obtained from the advance statements, and from patients and professionals in relation to the statements, reveal that patients did not always realise the importance of the booklets and were not encouraged to do so by mental health clinicians who were uncertain of their relevance and/or usefulness.

This study, is probably telling us that without buy-in commitment from professionals and patients, psychiatric advance statements will not affect outcomes. The only successful study from Henderson et al (2004) provides proof that if mental health professionals who recognise the importance of psychiatric advance statements are in administrative positions to lead projects on the implementation of such instruments, studies can be effective but not necessarily patient led. Most initiatives to do with patient choice now must be led by patients. Therefore the generalisability of Henderson et al's (2004) study needs to show that the initiative can be led by patients (19).

Government legislation is also pushing towards more patient choice but American experience shows that legislation without clear guidelines of implementation and lack of 24 hour access to psychiatric advance statements by mental health providers "may do little more than the act of scrawling 'help' on a scrap of paper, stuffing it into a bottle, and hurling it into the ocean."(25) (p. 439)

Advocacy is one solution but it is difficult without equality of status. As the study by Meier et al (1996) on medical advance directives has shown, providing counselling to patients by counsellors from the hospital's office of patient

representatives who are trained on the legal aspects of the documents, is an effective way of increasing rates of completion in secondary care (64).

Finally, gradual change in society to give more emphasis to patients' rights and wishes and increasing desire for empowerment by patients, might provide fertile ground for successful implementation of psychiatric advance statements.

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# APPENDICES

## *PREFERENCE FOR CARE STUDY*

University Department of Psychiatry  
Royal Free Hospital

Tel:                      Ext.  
Fax:

This study aims to demonstrate whether preferences for care provided by patients with severe mental illness have a positive impact on pathways to subsequent care including greater compliance with medication, less use of involuntary admissions and increased patient and professional satisfaction with services.

All patients admitted under sections 2, 3 and 4 to the acute psychiatric units of the Royal Free Hospital Hampstead Trust and St. Ann's Hospital, Tottenham will be eligible to take part. As close as is practicable to discharge from the section, each patient who gives informed consent will take part in a structured interview. This will assess the type of care encountered on the pathway to admission, their current mental state and their social functioning. Information from the casenotes will also be recorded. After this assessment interview, patients will be randomly allocated into 2 groups. Patients in group 1 will not be asked any further questions and will receive standard care. Patients in group 2 will be asked in an open fashion about the circumstances of their admission under Section, their views about the procedure and how such a situation might have been managed differently. They will then be asked to complete a one page preference form in which they will state their wishes should the circumstances arise in the future that might lead to similar use of the Mental Health Act. Where possible, a close relative, friend or carer will be involved in helping the patient identify preferences for future care, and the research fellow will liaise with relevant professionals to check the feasibility of the patient's choices. It will be stressed to patients (and relatives) that the preferences for care have no legal status. Neither patients nor professionals will be in any way bound by them. The preference forms obtained from patients in group 2 will be distributed to the patient and (where possible a relative/carer), their key worker, responsible medical officer, CPN, and general practitioner.

Follow-up: All patients will be followed up to 12 months. The follow-up will involve examination of the patients hospital records over the past year, and an interview involving brief questions about pathways to recent care and a structured questionnaire concerning their satisfaction with services over the previous year. Those in the preference for care group will also be asked whether their preferences were ever invoked and their view of the relevance and importance of what was contained in the preference form. The views of the relevant staff (key worker, consultant, CPN and GP) will also be obtained as to whether the preferences for care were ever acted upon, their views as to their usefulness for each patient, and the number of community visits they have made concerning each patient over the follow-up period.

If you would like further information please contact:

Alexia Papageorgiou, Research Fellow, Tel:                      ext.

**APPENDIX 2: Informed consent**

**STUDY OF PATIENTS' ADVANCE DIRECTIVES**

Dear Sir/Madam,

We are studying people who have been admitted to hospital on section.

We would like you to take part in a short interview about how you are now. This includes your feelings as well as how you are getting on in the world socially.

Some of you will be asked to give us your instructions regarding what you would like done should you be faced with another compulsory admission in the future.

We will want to contact you again for a brief interview in about 12 months. We will also want to look at your records at that time.

If you do not wish to take part in this study your decision will not affect your care in any way.

Thank you for your help.

Prof Michael King

Dr Oliver Davidson

I \_\_\_\_\_

of \_\_\_\_\_

agree to take part in this study

Signed \_\_\_\_\_

Date \_\_\_\_\_

**APPENDIX 3: Basis-32 questionnaire**

BASIS 32-C

Copyright 1985 by Evaluative Service Unit, McLean Hospital



PLEASE TURN TO BACK PAGE TO COMPLETE THE FORMS





**APPENDIX 4: HoNOS scale**

**Glossary** for completion of HoNOS Chart  
Background Information

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## HoNOS Chart – Background Information

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## HoNOS Chart - Scales

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APPENDIX 5: Hospital Service Satisfaction scale

Hospital-Service Satisfaction

Listed below are a number of items relating to the care given by the hospital staff. We would like to know how satisfied or dissatisfied you are with all aspects of this service. Please make sure you answer all questions.

“What is your overall feeling about.....”

1. The amount of help you received.

5 excellent      4 mostly satisfied      3 mixed      2 mostly dissatisfied      1 terrible

2. The kind of service (offered).

5 excellent      4 mostly satisfied      3 mixed      2 mostly dissatisfied      1 terrible

3. How this service may have helped improve the relationship between you and your relatives/close friends.

5 excellent      4 mostly satisfied      3 mixed      2 mostly dissatisfied      1 terrible

4. How this service may have helped you to cope with your problems.

5 excellent      4 mostly satisfied      3 mixed      2 mostly dissatisfied      1 terrible

“What is your overall feeling about.....”

5. How this service may have helped you establish good relationships with people outside your family (e.g. friends, neighbours, etc).

5 excellent      4 mostly satisfied      3 mixed      2 mostly dissatisfied      1 terrible

6. Willingness of the staff to understand your problems.

5 excellent      4 mostly satisfied      3 mixed      2 mostly dissatisfied      1 terrible

7. Respect given by staff for your rights as an individual.

5 excellent      4 mostly satisfied      3 mixed      2 mostly dissatisfied      1 terrible

8. In an overall or general sense, how satisfied are you with the service you have received.

5 excellent      4 mostly satisfied      3 mixed      2 mostly dissatisfied      1 terrible

9. To what extent do you think that the psychiatric treatment that are now receiving/have received is right for you?

5 excellent      4 mostly satisfied      3 mixed      2 mostly dissatisfied      1 terrible

APPENDIX 6: Baseline additional information form

ADDITIONAL INFORMATION

HOSPITAL NUMBER

Name and Address of participant

\_\_\_\_\_

Tel: \_\_\_\_\_

1. First ever section? Yes \_\_\_\_\_ No \_\_\_\_\_

2. Diagnosis \_\_\_\_\_

\_\_\_\_\_

3. Name of Consultant \_\_\_\_\_

4. Name of key-nurse \_\_\_\_\_

5. Last ever job and when

\_\_\_\_\_

6. Name, address and telephone number of GP

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

7. Name, address and telephone number of Social Worker

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

8. Date and Nature of discharge from section

i.e. a) Expired

b) Discharged by consultant

c) By Mental Health Tribunal

9. On Supervision Register? Yes \_\_\_\_\_ No \_\_\_\_\_

10. Number and length of previous admissions whether formal or informal in last five years \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**APPENDIX 8: Letter to patients' GP**

Date:

Re:

Dear Dr

We are studying patients who during their recent psychiatric admission to hospital have been on a Section. The above named patient has completed a "Preference for care" booklet which details early warning signs of illness and their wishes should their condition deteriorate. A copy of the booklet has been given to the patient, their key-worker, and one placed in the medical notes. Enclosed is a copy for your notes. It is hoped that the instructions will be acted on whenever appropriate.

Patients will be followed up 1 year after entering the study, and we will assess whether the patient's instructions had an impact on subsequent care e.g. improved satisfaction, compliance or less compulsory admissions. This may involve accessing minimal information from GP notes but we will contact you nearer the time if required.

Thank you for your help and participation in this study. Please contact me at the above number (ext.                   ) if you require further information.

Yours sincerely

Alexia Papageorgiou (Research Fellow)

**APPENDIX 9: Follow-up letter to patients**

29/10/99

Dear,

You may remember that in October 1998 you took part in the Preference for Care Study. As it was mentioned to you at the time I would like to see you a year later to find out how you have been, and whether you are happy with the care you have received.

I have already spoken to your CPA key-worker who suggested that if I could visit you at your place, it would be more convenient for you. I could come around your place next Thursday 4/11/99 at about lunchtime.

I would appreciate it if you could call me on \_\_\_\_\_ or \_\_\_\_\_ ext. \_\_\_\_\_ in order to confirm the appointment.

I am looking forward to hearing from you.

Yours sincerely

Alexia Papageorgiou  
Research Fellow



**APPENDIX 10: Follow-up letter to mental health professionals**

Date:

Re:

Dear

We are studying patients who during their recent psychiatric admission to hospital have been on a Section of the Mental Health Act. The above named patient has participated in this study, the Preference for Care Study, and has been followed-up.

Enclosed is a short questionnaire and I would be grateful if you could complete it and return it to me at the address below (specify Block ).

Thank you for your help and participation in this study. Please contact me at the following number ) if you require further information.

Yours sincerely

Alexia Papageorgiou  
Research Fellow

APPENDIX 11: Self-efficacy questionnaire

**GENERALISED SELF-EFFICACY SCALE**

NAME: \_\_\_\_\_

DATE: \_\_\_\_\_ RECORD NUMBER: \_\_\_\_\_

	Not at all true	Barely true	Moderately true	Exactly true
1. I always manage to solve difficult problems if I try hard enough.	1	2	3	4
2. If someone opposes me, I can find means and ways to get what I want.	1	2	3	4
3. It is easy for me to stick to my aims and accomplish my goals.	1	2	3	4
4. I am confident that I could deal efficiently with unexpected events.	1 1	2 2	3 3	4 4
5. Thanks to my resourcefulness, I know how to handle unforeseen circumstances.	1 1	2 2	3 3	4 4
6. I can solve most problems if I invest the necessary effort.	1	2	3	4
7. I remain calm when facing difficulties because I can rely on my coping abilities.	1	2	3	4
8. When I am confronted with a problem, I usually find several solutions.	1	2	3	4
9. If I am in a bind, I can usually think of something to do.	1	2	3	4
10. No matter what comes my way, I am usually able to handle it.	1	2	3	4
11. I can manage my own mental health.	1	2	3	4
12. I can make decisions about my future care.	1	2	3	4
13. If I need hospitalisation in future I can voluntarily admit myself.	1	2	3	4
14. I can contact my GP/KW/outpatient clinic, the next time I begin to relapse.	1	2	3	4

**APPENDIX 12: Patients' follow-up questionnaire**

Do you remember drawing up a preference for care booklet?
Do you still have it?
Could you show it to me?
If No what happened?
Was it ever used in your care the last year?
If yes whose idea was to use it?
Was it helpful?
If Yes how?
If No why not?
Would you want to use it again?
Would you recommend it to other patients?
In what way do you think it could be improved?

**APPENDIX 13: Semi-structured questionnaire on mental health professionals' views regarding patients' preference for care booklets**

Do you remember if this patient had a preference for care booklet?
Did you ever see it?
Did you ever use it in the management of this patient?
Did you find it useful in the management of this patient?
If Yes why?
If No why not?
How useful do you think this instrument is?
How do you think it would be improved?
Would you want to use it again?

APPENDIX 14: Follow-up additional information form

FOLLOW-UP

HOSPITAL NO \_\_\_\_\_ WARD \_\_\_\_\_ STUDY NO \_\_\_\_\_ P / C

DATE: \_\_\_\_\_

PATIENT'S DETAILS

NAME \_\_\_\_\_ D.O.B. \_\_\_\_\_

ADDRESS \_\_\_\_\_

TELEPHONE \_\_\_\_\_

NEXT OF KIN ADDRESS \_\_\_\_\_

TELEPHONE \_\_\_\_\_

DISCHARGE DETAILS

DATE OF ADMISSION \_\_\_\_\_

DATE OF DISCHARGE \_\_\_\_\_

MEDICATION AT DISCHARGE \_\_\_\_\_

MEDICATION AT FOLLOW-UP \_\_\_\_\_

INITIAL TYPE OF SECTION 2  2-3  3  4  4-2  4-3

DATES ON EACH SECTION \_\_\_\_\_

DATES OF DISCHARGE FROM SECTION \_\_\_\_\_

NATURE OF DISCHARGE FROM SECTION

- a) Expired
- b) Discharged by consultant
- c) By Mental Health Tribunal

**DATES AND TYPES OF SECTIONS FOR SUBSEQUENT ADMISSION:**

- 1) DATE \_\_\_\_\_ TYPE OF SECTION \_\_\_\_\_
- 2) DATE \_\_\_\_\_ TYPE OF SECTION \_\_\_\_\_
- 3) DATE \_\_\_\_\_ TYPE OF SECTION \_\_\_\_\_
- 4) DATE \_\_\_\_\_ TYPE OF SECTION \_\_\_\_\_
- 5) DATE \_\_\_\_\_ TYPE OF SECTION \_\_\_\_\_

**OUTPATIENT INFORMATION**

NUMBER OF OUTPATIENT APPOINTMENTS BOOKED \_\_\_\_\_  
NUMBER OF OUTPATIENT APPOINTMENTS KEPT \_\_\_\_\_

**COMPLIANCE WITH DEPOT**

REGIMEN (i.e. 1 weekly) \_\_\_\_\_  
NO OF DEFAULTS \_\_\_\_\_

**MENTAL HEALTH ACT**

WHAT WAS THE CPA STATUS AT DISCHARGE? 1  2  3  S R

**FOR PATIENTS ON SUPERVISION REGISTER**

DATE OF DISCHARGE OFF REGISTER \_\_\_\_\_

WHAT WAS THE SECTION RATE FROM ENTRY TO THE STUDY TO FOLLOW-UP?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**APPENDIX 15: An example of a completed preference for care booklet**

**Preference for care booklet # 150**

Statement 1: "I notice I am becoming ill again when I....."

- Loose my sleep
- Take on too many tasks without completing them

Statement 2: "Things that happened just before I was placed on a section and/or started to become ill were..."

- Bursting out in tears
- Take on too many tasks without completing them
- I was not making any sense when talking to people

Statement 3: "If I do seem to be becoming ill again I would like..."

- To talk to someone who will understand my problems e.g. a counsellor
- To be informed before sectioning about the reasons for being sectioned
- My next of kin to have a saying in whether or not I should be sectioned

Statement 4: "I would like you to contact..."

- My mother
- My brother
- A counsellor or any social worker or my community nurse

Statement 5: "I wouldn't want..."

- To be sectioned again
- To be put on Haloperidol

Statement 6: "If I have to be admitted to hospital again I would like..."

- In the ward round things to be discussed rather than me being interrogated
- My own room
- To receive regular counselling

Statement 7: "In hospital I would also like..."

- To be allowed to go out when I feel like doing it
- To have an independent advocate
- To know more about the decisions regarding my care and have a saying about these decisions

**Please see a hard copy of a preference for care booklet at the  
back of thesis**

**APPENDIX 16: Published papers**



RESEARCH AND EVALUATION

**Advance directives for patients compulsorily admitted to hospital with serious mental disorders: Directive content and feedback from patients and professionals**

ALEXIA PAPAGEORGIU<sup>1</sup>, ANIS JANMOHAMED<sup>1</sup>, MICHAEL KING<sup>1</sup>,  
OLIVER DAVIDSON<sup>1</sup>, & JOHN DAWSON<sup>2</sup>





















## **Advance directives for patients compulsorily admitted to hospital with serious mental illness**

Randomised controlled trial

ALEXIA PAPAGEORGIU, MICHAEL KING, ANIS JANMOHAMED,  
OLIVER DAVIDSON and JOHN DAWSON















## **Legal pitfalls of psychiatric research**

JOHN DAWSON, MICHAEL KING, ALEXIA PAPAGEORGIOU  
and OLIVER DAVIDSON





