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An investigation to examine the relationship between illness representations, quality of life and treatment adherence amongst young adults (aged 17-30 years) with insulin dependent diabetes

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UNRESTRICTED

**PHILIPPA HESTER-SMITH**

**AN INVESTIGATION TO EXAMINE THE RELATIONSHIP BETWEEN  
ILLNESS REPRESENTATIONS, QUALITY OF LIFE AND TREATMENT  
ADHERENCE AMONGST YOUNG ADULTS (AGED 17-30 YEARS) WITH  
INSULIN DEPENDENT DIABETES**

**Submitted in partial fulfilment of the requirements for the degree of Doctor of  
Clinical Psychology (D. Clin. Psy).**

**17th July 1998**

**Salomons  
Canterbury Christ Church College**

**(word count 19,467)**

**DATE OF SUBMISSION: 16 SEPTEMBER 1998**

**DECLARATION**

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed P. Nester (candidate)

Date 6<sup>th</sup> July 1998

**STATEMENT 1**

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed P. Nester (candidate)

Date 6<sup>th</sup> July 1998

Signed John Wetherman (supervisor)

Date 7<sup>th</sup> July 1998

**STATEMENT 2**

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and abstract to be made available to outside organisations.

Signed P. Nester (candidate)

Date 6<sup>th</sup> July 1998

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## ABSTRACT

This study explored treatment adherence amongst young adults aged 17-21 years and 23-30 years with insulin dependent diabetes. The Self-Regulatory Model (Leventhal, Nerenz & Steele, 1984) was drawn upon and the aim was to examine the relationship between treatment adherence and three independent variables including illness perceptions, medication beliefs and perceived quality of life.

The sample included seventy-seven male and female participants who were recruited from four outpatient hospital clinics within the South of England. Thirty-seven participants were aged between 17-21 years and thirty-nine aged between 23-30 years. Self reported measures of treatment adherence and haemoglobin blood test results revealed that many participants were struggling to maintain good glycaemic control. Furthermore, significant differences between age groups were revealed within self report adherence measures with the younger age group reporting greater non adherence to glucose testing and diet.

A non parametric correlation design was used to determine whether there was a relationship within each age group between measures of treatment adherence and the independent variables. No relationship was found between Illness perceptions and treatment adherence, although medication beliefs were associated with insulin misuse concerning weight control within the younger age group only. Furthermore, positive associations were found between quality of life measure, insulin adherence and glycaemic control within both age groups.

The results are discussed in relation to the Self Regulatory Model and it is suggested that the association between quality of life and treatment adherence requires further exploration. Future research proposals are outlined and the clinical implications of this study are discussed in some depth.

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## **1. INTRODUCTION**

This study aims to focus upon the link between cognitions, adherence, quality of life factors and treatment adherence in young adults aged 17-30 years with Insulin Dependent Diabetes. The theoretical framework will be drawn from Leventhal, Nerenz and Steele's (1984) Self Regulatory model and the findings will be explored from a clinical perspective including the potential implications for self management interventions. Before reviewing previous research in this area there will be a brief introduction to the nature of diabetes and its management

### **1.1 The Nature of Diabetes**

Diabetes Mellitus is a serious medical condition involving abnormalities in glucose metabolism. Glucose is an important metabolic fuel which provides energy for many types of cells including fat, muscle and brain cells. Normally it is regulated by the pancreatic hormone insulin and diabetes results from deficiencies in its production or utilisation.

There are two forms of diabetes are namely Non Insulin Dependent Diabetes Mellitus (NIDDM) and Insulin Dependent Diabetes Mellitus (IDDM). The former, NIDDM, is thought to have a hereditary component although it has also been associated with obesity (Zimmerman, 1990). It is characterised by impaired beta cell functioning which results in insufficient insulin or insulin resistance in the muscle, liver and gut. This impairs the uptake of glucose and oral medication and dietary restriction is generally sufficient to control the condition.

In contrast IDDM results from insulin-producing pancreatic beta cells which are actually destroyed via a combination of genetic and auto-immunological processes



(Cox, Gonder-Frederick, Pohl & Pennebaker, 1986). In this instance daily injections of insulin are required alongside other self-care activities (see below).

As this study is most concerned with Insulin Dependent Diabetes the remainder of this section will focus purely upon this type of diabetes:-

### **1.1.2. Prevalence**

Within the United Kingdom 1.4 million (three percent) of the adult population suffer from diabetes, of whom 19-35 percent are insulin dependent (BDA, 1995). The onset of IDDM usually occurs in childhood or adolescence although it can develop at any age (Hampson, 1997). Furthermore it is equally common amongst males and females (Edwards, Baird, & Toft, 1991).

### **1.1.3. The Onset of Diabetes**

With the onset of diabetes the lack of insulin causes blood glucose to accumulate in the blood stream. This results in hyperglycaemia which may lead to serious medical complications. The acute symptoms of hyperglycaemia include excessive urination, thirst and weight loss. Underlying these symptoms are the build up of ketones in the blood stream resulting from incomplete breakdown of fat in the liver and adipose tissues. If ketones are left undetected diabetic ketoacidosis leads to coma and death. Sadly in the United Kingdom ketoacidosis is the single largest cause of death amongst diabetic people under the age of twenty (Wood, 1997).

To avoid hyperglycaemia diabetics need to take insulin injections to utilise glucose in the bloodstream and to lower blood glucose levels. However, if blood sugar circulating in the bloodstream drops too low a state referred to as hypoglycaemia develops. Hypoglycaemia poses immediate threats to health as the brain is reliant

upon glucose as a primary source of metabolic energy. Thus moderate hypoglycaemia can cause mental confusion, slurred speech, poor motor co-ordination and mood changes. Furthermore if it becomes severe it could lead to fainting, seizures, coma and even death.

The onset of hypoglycaemia is often sudden, unpredictable and can be frightening, unpleasant, socially embarrassing and even life threatening (Gonder-Frederick & Cox, 1991; Kyngas & Hentinen, 1995). Therefore the sufferer has to steer between avoiding hypoglycaemia whilst also ensuring that their blood glucose levels do not rise too high. Indeed avoiding hyperglycaemic states is particularly important as it is associated with long term medical complications (Reichard, Nilsson & Rosenqvist, 1993) including retinopathy, vascular disease, neuropathy and nephropathy.

Retinopathy is caused by ischaemic changes in the retina, including the development of minute aneurysms (distended sections of blood vessels), bleeding and retinal detachment which is a major cause of blindness (Lipsett, 1980). Vascular Disease is associated with circulatory problems, ulceration, amputations, impotence and cardiac problems. For example, diabetics are four times more likely to experience heart disease (Klein, Moss & Klein, 1992).

Neuropathy may also result from changes in motor, sensory and autonomic nerves within the peripheral nervous system and this can lead to numbness particularly in the peripheral areas such as the feet. Regular foot examinations are therefore necessary to check for infection and ulceration.

Finally nephropathy (kidney damage) is one of the most serious complications which leads to approximately 14 percent of all deaths of people with diabetes (Edwards et al., 1991).

#### **1.1.4. Diabetes Treatment**

To reduce the risks of diabetic medical complications the recommended glucose levels within the blood stream should be kept near to the normal range (i.e 89-150 mg/dl, or 4-7 M/L). This is achieved through a complex regime including daily insulin injections, glucose testing, diet and exercise:-

Insulin products until recently were derived entirely from animal sources (Bovine, Porcine), although over the past 10-15 years genetically engineered human insulin has largely replaced animal forms. Whilst it was once common for people to be maintained on a single injection of insulin per day, doctors now often advise between two to four injections daily. This is because there is growing evidence that even slight hyperglycaemic states may increase the risk of medical complications (Reichard et al., 1993).

Regular glucose tests are also needed at least once a day to monitor the fluctuation of glucose levels. This test involves a finger prick sample of blood being placed upon a specially treated reagent strip which is then read by an electronic meter. In addition a daily urine test will also check for ketones associated with extreme hyperglycaemia.

Meals of known caloric value must also be eaten at regular intervals to match the peaks and action of the injected insulin. Furthermore additional calories are needed when physical activity increases and a source of sugar has to be readily available for episodes of hypoglycaemia. Regular exercise is also recommended as it may reduce the risk of cardiovascular disease (Wasserman & Zinman, 1994). Additional care has to be taken during periods of ill-health and stress as physiological factors may also raise the amount of glucose released into the blood stream (Wood, 1997; Hanson, Henggeler & Burghen, 1997).

## **1.2 Treatment Adherence**

The Diabetes Control and Complication Trials (1993), which was replicated in Sweden (Reichard, et al., 1993), has confirmed that intensive management which keeps blood glucose near the normal range prevents long term medical complications. In addition the relationship between control and complication was so strong that even modest reductions in blood glucose levels were associated with reductions in complications. This suggested that for patients where tight glucose control appears too ambitious any improvements made will reduce the risk of complications (Hampson, 1997).

Adherence to treatment is a crucial factor in maintaining safe blood glucose levels. Unfortunately as with any complex, demanding, lifelong treatment programme people may experience difficulties in adhering to their treatment regime (Epstein & Cluss, 1982). This may be relevant to those who are entering into adulthood as they face unique challenges including decision making in the areas of marriage, vocation and child-bearing in the context of declining parental influence (Wiebe, Alderfer, Palmer, Lindsay & Jarrett, 1994).

In recent years problems with poor attendance to outpatient clinics by young adults has been highlighted and in response clinics specifically for young adults aged 17-30 years have been established (Eiser, Flyne, Green, Tavermans, Kirby, Sanderman, & Tooke, 1993) . However this age group criterion is broad, incorporating those within the transitional period to adulthood (e.g 17-22 years) and those more established in adulthood (e.g. 23-30 years).

Several theorists have drawn attention to the difficulties people face during transitional times. For example, Erikson (1963, 1968) described late adolescence as

involving an "Identity Crisis" whereby self identity may be appraised and modified in the advent of role changes alongside the formation of new and intimate relationships. A few studies have begun to explore the impact of chronic illness upon self identity in adolescence and suggesting that diabetes may impact upon this process (Hentinen, & Kynas, 1996) especially in relation to reduced self esteem (Swift, Seidman & Stein, 1967).

Levinson, Darrow, Klein, Levinson, Mckee, (1978) and Blos (1962,1967) also draw attention to role changes and separation issues during early adulthood i.e outwardly this may be denoted by such phenomena as increasing financial independence, moving out of the family home and entering new, more autonomous and responsible roles. Internally this may involve increasing differentiation between self and parents, greater psychological distance from the family and reduced dependency on parental support and authority.

Blos (1962) has also drawn attention to the potential dilemmas of young adulthood. The strive towards greater freedom in decision making also brings forth the harsh realities of having to fight their own battles. This may become a daunting prospect. Furthermore he highlights potential loss issues resulting from the emotional and or physical separation (e.g. leaving home) from important attachment figures. For many there may be a period of homesickness, depression or loneliness and for some this may continue for a considerable time (Anderson, 1990).

Blos, (1962) has also drawn attention to the greater fragility of adolescent sexual relationships and suggests that the search for intense but often short-lived relationships is a way of coping with potential inner emptiness (although these suggestions would need to be empirically validated). What is clear is that more individuals enter into sexual relationships during adolescence (Coleman, 1980) and for young adults sexuality may be an integral part of their self identity. Problems may

arise for young men with diabetes facing impotence problems through associated medical complications or for diabetic women contemplating pregnancy.

The degree of emotional turmoil during the transition to adulthood was debated by Coleman (1960) who suggested that late adolescence was not necessarily a period of "stress and storm" as implied within psychoanalytic literature. Whilst he acknowledged the major biological and psychological changes which occurred through adolescence he suggested that adjustments should be taken one at a time in order to minimise the risk of overwhelming levels of stress (i.e. focal points of change).

Despite the potential for more gradual change through adolescence the challenges of the transition to adulthood may be more complex for adolescents with Insulin-dependent Diabetes. For example studies on adolescence and young adulthood have found diabetics reported a lower mean level of general well-being than non diabetic participants (Tebbi, Bromberg, Sills, Cukierman, & Piedmonte, 1990). Furthermore some differences were found in terms of workplace experiences as participants with diabetes reported more difficulties in performing in their jobs and a greater degree of worry about maintaining their concentration at work (Tebbi et al., 1990).

In addition, with the onset of diabetes, people are faced with serious health threats which may enhance their awareness of mortality at an earlier stage in their life cycle than those without chronic illness. For example, Hentinen and Kyngas', (1996) study revealed that many adolescents with diabetes reported fears of death associated with hypoglycaemia. Those in late adolescence have in addition to live within social environments which may oppose good diabetic treatment regimes. For example, they may have to face social pressures to consume large amounts of alcohol, smoke, or engage in unhealthy eating.

Some of the issues outlined above are very relevant for those in their twenties who are more established in adulthood. However peer and social pressures may change and as more people enter into a cohabiting or a marital relationship additional social support may be more readily available. They may also be more likely to be facing new transitions such as career changes or entering parenthood. The birth of a baby also demands major changes for a couple as they negotiate changes in their interpersonal relationship, social and work roles.

Potentially there are differences between those age 17-22 years and 23-30 years in terms of life stage although caution is needed not to make generalisations when reviewing life stages as each person has a unique life history. Nevertheless, as part of this study it would be of interest to examine whether there are differences between these age groups in terms of their adherence to treatment regimes, quality of life and cognitions about diabetes.

### **1.2.1 Measuring Treatment Adherence - Methodological Issues**

The extent to which young adults neglect their treatments has been examined. However, studies have been drawn mainly from people attending diabetes clinics. This may underestimate the problem as it is known that non-attenders are less engaged with their treatments (Hammersley, Holland, Walford & Thorn, 1985). Furthermore, studies need to take into account all the components of treatment and take into account that adherence may change over time.

The accurate assessment of treatment adherence is also affected by the fact that people may inadvertently mismanage self-care due to poor instruction or inconsistent advice from the medical profession. For example, Kinmonth and Marteau, (1989)

reported a considerable discrepancy between consultants and general practitioners as to what they would regard as an acceptable and safe blood glucose level.

The measurements for treatment adherence include a) self report and b) physiological measures involving serum glycosylated haemoglobin (HbA1c) which reflect glucose levels over 6-8 weeks (Anderson, Auslander, Jung, Miller & Santiago, 1990).

However both of these types of measures may be problematic.

Self report measures (e.g. interviews, questionnaires and diaries) may involve subjective bias relating to selective memory recall and social desirability (Gordis, 1976) which may potentially underestimate rates of non-adherence (Epstein & Cluss, 1982; Wilson & Endres, 1986). Furthermore, some studies fail to use self report measures that have been standardised and validated.

In contrast physiological measures may measure factors apart from adherence. For example researchers who have not found a relationship between HbA1c and self report measures have drawn attention to the influence of biological factors on glucose control (e.g. Glasgow, McCaul & Schafter, 1986; Hanestad & Albrektsen, 1991). On the other hand researchers who have found a significant relationship emphasise the validity of HbA1c as a measure of adherence (e.g. Hanson, De Guire, Schinkel, Kolterman, Goodman, & Buckingham, 1996; Brownlee-Duffeck, Peterson, Simonds, Goldstein, Kilo & Hoette, 1987; Hentinen & Kyngas, 1996). However, the discrepancies between these studies may be due to differing methods of assessment (Dunbar-Jacob & Schlenk 1996) and different interpretations of data. For example, Hentinen & Kyngas' (1996) study, which found a positive relationship between self reported adherence and blood glucose control considered an HbA1c range of 6.5 to 12.8 M/L as indicating good/satisfactory control. This contrasts with other studies which would have interpreted the higher end of this range as representing poor metabolic control, (Hanson et al., 1996) and therefore unrelated to self reported



adherence. In the light of such uncertainty the assumption of HbA1c as a reliable indicator of adherence needs closer empirical examination. This study aims to explore this relationship further within a sample of young adults.

### **1.2.2 Review of Studies Examining Treatment Adherence In Young Adults**

Despite problems measuring adherence a few studies have focused specifically upon a young adult sample (although the age ranges have differed between studies):-

Kovacs, Goldston, Obrosky & Lyengar, (1992) conducted a nine year longitudinal study of children (aged 8-13 years) and found that 17 to 19 year olds were at greater risk of non-adherence and had poorer glucose metabolic control than other age groups. Furthermore, Wysocki, Hough, Ward & Green's, (1992) study found that poor adjustment to treatment regimes in adolescents persisted into early adulthood (18-22 years). They also found a high incidence (31 percent) of microalbuminuria (early stages of neuropathology) which was associated with consistently high blood glucose levels.

Studies have also revealed a variance between the different components of treatment with reported adherence to insulin injections being greater than glucose testing, diet, and exercise. For example, a study conducted by Peveler, Davis, Mayou, Fairburn and Mann, (1993), involving a large sample (N=113) of young adults (aged 17-27) revealed that 98 percent were conscientious about administering insulin. On the other hand 33 percent of female participants reported that they manipulated the amount of insulin injected for the purpose of body weight reduction. These findings were supported by Dunning's, (1995) study which revealed from a sample of fifty-nine young adults (aged 17-33) that 38 percent of women reported to have taken less insulin to aid weight control.

Glucose testing is another important self care activity as young adults will need to be aware of their glucose levels in order that insulin levels, diet and exercise can be adjusted accordingly. Unfortunately studies based upon self-report measures have revealed that adherence to glucose testing is poor. For example, Dunning's, (1995) research revealed that 33 percent of young adults did not perform regular daily glucose tests and a third of these did not perform glucose tests at all. These results are comparable with the study by McCaul, Glasgow & Schafer's, (1987) that found seven percent of young adults openly admitted to never testing their blood glucose levels.

Gonder-Frederick, Cox, Pennebaker, & Bobbit (1986) suggest that individuals may be less reliant on glucose tests because they believe that they will be able to detect change in glucose levels through subjective physical symptoms. However their research examining the reliability of subjective information revealed a tendency for participants to underestimate hyperglycaemic states and overestimate hypoglycaemic states. They also showed a high rate of "false alarms" i.e. tending to mis-attribute physical symptoms to their diabetes rather than to other environmental or interpersonal situations. Furthermore, the ability to estimate glucose fluctuations correctly also varied across individuals ranging from 49 to 90 percent accuracy rates (Gonder-Frederick & Cox, 1990), although this was unrelated to the participant's perceived competence. Therefore the authors emphasised the need for objective measures of blood glucose i.e through testing.

Finally concerning diet and exercise, available evidence suggests that a significant proportion of diabetics are lax in following a recommended low fat diet despite food intake being an extremely important contributor to metabolic control (Burroughs, Pontious, & Santiago, 1993; Balfour, White, Schiffrin, Dougherty & Dufresne, 1993). The degree to which young adults prioritise physical activity has not been well

researched. This may be because exercise has not been significantly related to glycemic control (Hanson, et al., 1997) although regular exercise might relate to glucose control in the longer term and may reduce the risk of cardiovascular disease (Wasserman & Zinman, 1994).

### **1.3 Understanding Treatment Adherence**

Having identified the extent of non-adherence to treatment regimes amongst young adults this section will focus on factors influencing health related behaviours amongst people with diabetes. Since there is relatively little research on young adults the review will incorporate studies across a broader age range including adolescents and adults.

A number of different theoretical models have attempted to understand health related behaviours although none have been entirely satisfactory. Traditional medical models tended to view treatment noncompliance as deviant behaviour due to ignorance or personality pathology. This can be criticised for its simplicity and lack of empirical support. In contrast environmental and emotional factors have been considered and despite appearing to give more plausible explanations studies have resulted in inconsistent findings. However in recent years within the field of health psychology effort has been channelled into the exploration of cognitive factors resulting in social cognition's models and self regulation theory (Leventhal et al., 1984). The latter appears the most promising theory in terms of clinical value. However, before this is explored, a brief overview of the other models will be given.

#### **1.3.1. Traditional Medical Approaches**

The initial focus within the medical profession was on the link between poor adherence and a lack of knowledge (Stone, 1964, Sanazaro, 1985). Indeed few

illnesses require the person to acquire as much information and new skills as IDDM. However despite knowledge being a crucial requisite to adequate self-treatment it has not explained the apparent widespread disengagement with self care activities for the management of diabetes amongst young adults. Furthermore, educational interventions have not always resulted in improved self-treatment and diabetes control or may only produce short term benefits (Cox, et al., 1986; Williams, Martin, Hogan, Watkins & Ellis, 1967).

Therefore disenchanted with a purely knowledge based explanation some researchers turned their attention to personality factors. This resulted in a number of studies attempting to label "good" and "bad" personality characteristics (e.g. Simmonds, 1976-1977) although not surprisingly no unique personality profiles were found that predicted poor adherence (Dunn & Turtle, 1981; Koch & Molnar, 1979). Despite this personality attributes (e.g. selfishness and stubbornness) are discussed as having a detrimental effect on client-practitioner relationships (Bradley, 1982).

### **1.3.2 Environmental and Emotional Factors**

Despite controversy concerning the search for personality pathology this does not preclude the importance of environmental and emotional factors. In particular stress has been shown to affect metabolic control. For example Hanson, et al., (1997) found a relationship between stress and poor metabolic control in adolescents although social competence acted as a buffer against this negative effect.

The effects of stress upon high blood glucose may also be partially mediated by serious non-adherence to treatment (Goldston, Kovacs, Obrosky & Lyengar, 1995). For example, Balfour, et al., (1993) discovered blood glucose control was poorest in those women who both perceived their lives as stressful and reported medium to high disinhibition with food intake.

The presence of emotional disorders and other psycho-social problems may also interfere with treatment adherence (Murawski, Chazan, Balodimos & Ryan, 1979; Newbrough, Simpkins, & Maurer, 1985) although the results across studies are very inconsistent (Kovacs, Mukerji, Iyengar & Drash, 1996). For example, Kovac et al., (1992) found a relationship between serious non compliance and the onset of major psychiatric disorders later in life although they failed to account for the generally high levels (29%) of non adherence in late adolescence. Furthermore they failed to find a relationship between self-esteem, social competence, family functioning and treatment adherence. Conversely other studies suggest that these factors are important mediators of treatment adherence (Johnson, 1984, 1988; McCaul et al., 1987).

Quantitative studies have yet to examine the impact of quality of life upon treatment adherence although qualitative research by Hentinen & Kyngas, (1996) with adolescents (13-17 years) found that a perceived lack of well-being was associated with poor treatment adherence. It would be of interest to ascertain whether perceived quality of life amongst a sample of young adults with diabetes was also related to treatment adherence. This current study aims to explore this relationship further.

### **1.3.3 Social Cognition Models**

Within health psychology it was recognised that explanations so far were inadequate to explain the widespread problems with treatment adherence and as a result social cognition models began to emerge and be applied to health. These focused upon the influence attitudes and beliefs had upon behaviour. In particular the Health Belief Model (Rosenstock, 1974), Theory of Reasoned Action (Ajzen, & Fishbein 1980), Theory of Planned behaviour (Ajzen, 1985), Locus of Control (Rotter, 1954) and Attribution Theory (Weiner & Skipper, 1979) have all been drawn upon to understand

factors influencing health care behaviours. Each of these models will be briefly reviewed as follows:-

#### **1.3.4 Health Belief Model**

This model was devised by Rosenstock (1974) whose original work focused upon the reasons why people did not take proactive action before the onset of a disease such as attending screenings and engaging in healthy behaviours etc. The model suggested that personal beliefs about the perceived seriousness of a health threat and perceived susceptibility to it guided behaviour. The model also suggested that people engage in weighing up the perceived costs and benefits of action.

Later the theory also drew attention to the importance of a stimulus or cues to trigger the behaviour (Becker & Maiman, 1975) and variables such as motivation (fairly non specific), orientation towards medication, doctor - patient relationships and personal attributes were incorporated. Therefore in relation to diabetes the health belief model suggested that for a person to adhere to their treatment they must be motivated, have certain cues for action in place, perceive the threat of their illness as high and for the benefits of adherence to outweigh the costs.

There has been some support for the health belief model as treatment adherence has been associated with the perceived seriousness of the illness and costs/benefits of treatment. For example, Hentinen and Kyngas, (1996) found that 73 percent of adolescents reported that a fear of complications strengthened their self discipline in situations where a neglect of self care might normally have been expected.

Furthermore, Lundman, Asplund, and Norberg's, (1990) research with adults revealed that the threat of complications acted as a motivation for self care. However other studies have drawn attention to the costs of striving for near normal blood glucose levels, suggesting that the fear of hypoglycaemia may be a major psychological

barrier to diabetes control (Weiner & Skipper, 1979; Cox, et al, 1986). Furthermore positive moods can be induced by mild elevations of blood sugar (Gonder-Frederick & Cox, 1991).

Despite research supporting the view that a person engages in weighing up the cost and benefits of treatment (Bond, Aiken, & Somerville, 1992) the health belief model has been criticised for its simplicity. In particular the notion that health behaviour arises from a one off rational decision lacked face value as it failed to account for fluctuations in adherence over time. Furthermore, the model neglected the importance of other cognitions and did not specify the broader range of beliefs which may arise within the constructs of costs and benefits (Weinman & Horne, 1995).

### **1.3.5 Theory of Reasoned Action & Planned Behaviour**

The health belief model also failed to account for the social influences on behaviour and how the perceived costs/benefits are translated into action. An alternative approach the Theory of Reasoned Action (TRA) focused upon the relationship between attitudes, intentions and behaviour. Ajzen & Fishbein, (1980) who developed the theory described attitudes as a product of beliefs about the likelihood (perceived outcome) and importance (perceived value) of the planned action. For example a person may be more likely to use insulin if they believe that it will keep blood glucose under control. Furthermore subjective norms which encompass beliefs about how others will appraise their behaviour and motivation to comply were perceived to be important determinants of behaviour.

Later Ajzen (1985) added another two variables to the TRA to form the Theory of Planned behaviour (TPB). These included the perceptions of control that a person has over their own behaviour and the degree to which external resources may be perceived as barriers to behaviour. In this way the influence of self-efficacy and

environmental factors was added to the equation. Furthermore although no studies in the field of diabetes have specifically explored the applicability of TPB, research has drawn attention to the importance of self-efficacy. For example, self-efficacy beliefs have been found to predict various aspects of diabetes self-management particularly diet and exercise (Hurley & Shea, 1992; Kavangh, Gooley & Wilson, 1993).

### **1.3.6. Theory of Locus of Control**

The Locus of Control theory (Rotter, 1966) influenced by social learning theory (Rotter, 1954) also explored the importance of the consequences of a behaviour, including beliefs concerning whether the behaviour will be positively reinforced. The theory originally incorporated a dimension of control from internal and external locus of control. The former related to the extent to which the person feels that s/he has control over what happens in a situation and the latter to the degree to which a person perceives external factors to be the controlling force. More recently formulations in the health psychology field have separated external factors into two dimensions including, chance and powerful others (Wallston, Wallston & DeVellis, 1978).

The idea of control and associated self-efficacy links closely to TPB and research is emerging to support the theories. For example Bradley, (1994) found that beliefs about the degree of perceived control patients have over their diabetes can predict adherence to various aspects of self-care, well-being and treatment satisfaction (for review see Lewis & Bradley, 1994). For example NIDDM patients with a stronger perceived control over their diabetes had better glycaemic control, lower body weight and heightened psychological adjustment (Bradley, Lewis, Jennings & Ward, 1990). However perceived control may have been the result of these positive outcomes rather than their cause.



### **1.3.7. Attribution Theory**

Attribution theory (Weiner & Skipper, 1979) has drawn attention to the impact which the perceived cause of one's illness has upon coping behaviours. The theory describes various dimensions including internal and external attributions that vary on stability and globility. An internal cause (e.g. stress, shock, diet) within the person may invoke feelings of self blame whereas an external attribution locates the cause outside the individual (e.g. environment, hereditary). Turnquist, Harvey and Anderson (1988) have proposed that having a causal theory about one's illness can relate to better adjustment and coping but the evidence available indicates that such beliefs seem unrelated to self care (Hampson, Glasgow & Toobert, 1990; Hampson, Glasgow & Foster, 1995). Future research upon perceptions of the cause of fluctuating blood glucose levels may be of more significance as it relates to the construct of perceived control.

### **1.4 Self Regulatory Model**

The social cognition models have drawn upon some important dimensions including the cause, illness identity, perceived seriousness, cost & benefits of treatment action, consequences and control. However until recently no theory had attempted to encapsulate all of these dimensions to develop an overall understanding of health cognitions. Neither had a theory taken into account the dynamic nature of treatment adherence whereby coping behaviours are constantly appraised and refined. The Self-Regulation Model (SRM) proposed by Leventhal et al., (1984) sought to bring together and address some of the inadequacies within social cognition theories.

The SRM suggests that as a result of personal experience, family and social beliefs people create a mental representation of their illness in order to regulate their illness

behaviour and coping strategies (Leventhal, Diefenbach & Leventhal, 1992). Two types of representations are thought to occur in parallel with each other including an illness representation involving an objective conceptualisation of a health threat and a more subjective emotional representation.

As yet the theory has not given much attention to the emotional representation apart from acknowledging that it exists and can potentially interact with cognitive representations of illness. Instead more attention has been directed to illness representations which are thought to comprise of five dimensions. These include a set of symptoms with a label (**identity**), beliefs about the cause of the illness (**cause**), beliefs about the likely effects associated with the illness (**consequences**), ideas about how long the illness will last (**timeline**) and beliefs about the control or cure of the illness (**control/cure**). Furthermore although these components are distinct and can have specific effects on outcome they are not necessarily independent (Weinman, Petrie, Moss-Morris & Horne, 1996)

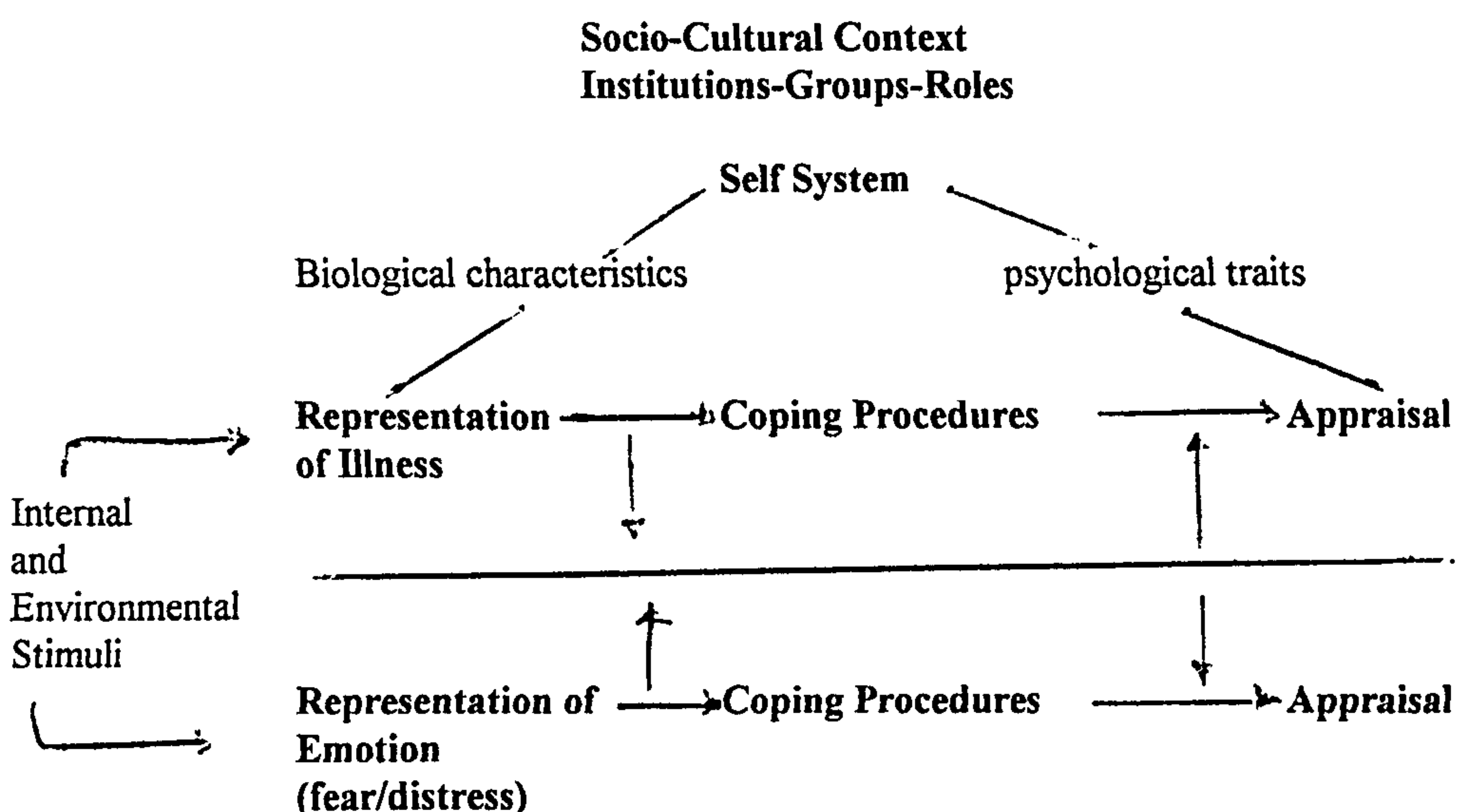
A second important feature of the SRM is an underlying processing system which comprises of a series of stages for guiding adaptive action . The first stage involves the development of an emotional representation and cognitive representation. This feeds into the second stage which develops an action or coping plan. The third stage involves the appraisal and evaluations of coping which feeds back to maintain or change behaviours.

Another important feature of the underlying processing system is that it is hierarchically organised. Each stage including the representation, action plans and appraisal can be thought of as a series of hierarchically arranged layers going from highly abstract material at the top end to more concrete situationally bound material at the bottom end. The abstract material may relate to memories of past experiences and social myths whilst more concrete material reflects general knowledge of

diabetes including doctors' advice. Thus whilst some of the self-referent illness perception an individual holds will be close to conventional medical or widely known knowledge about a particular illness some will be more divergent and idiosyncratic.

The theory also suggests that the degree to which abstract and concrete information is coherent is important as discrepancies can be stress-inducing and adversely effect treatment adherence. Such discrepancy may help to explain low adherence rates within chronic conditions as concrete and symptomatic aspects are thought to be more persuasive guides to action than the abstract knowledge a person has about a specific illness (Leventhal et al., 1992).

The SRM suggests that it is important to understand illness representations as they reflect the individual's unique way of making sense of the various threats and demands of illness. Furthermore such representations are thought to guide action and directly influence behaviours associated with management such as adherence and coping.



**Figure 1. Leventhal's self-regulatory model of illness (Adapted from Leventhal et al., 1992)**

Few studies have explored the five components within illness representations in relation to diabetes mainly because of the absence of operational measures. However,

two assessment measures have recently been developed including an Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris & Horne, 1996) and the Personal Models of Diabetes Interview (Hampson, et al., 1990). Only the latter measure has been used within the field of diabetes and to date only two studies on diabetes, treatment adherence and illness perceptions have been published.

The studies focused primarily upon older adults with Non Insulin Dependent Diabetes. The first study by Hampson, et al., (1990) found seriousness (e.g. consequences combined with time line) and treatment effectiveness (control) to be particularly important for adherence. The seriousness factor reflected the perceived seriousness and emotional reaction to their diabetes as well as their assessment of the consequences of their diabetes for various aspects of their lives. Furthermore the treatment effectiveness was composed of the perceived importance of the various regime components for controlling diabetes and patient feelings about following the regime.

Hampson et al., (1990) revealed that treatment effectiveness and seriousness were significant predictors of adherence to diet and exercise although they did not correlate with HbA1c (in which the authors attributed the influences of biological factors on metabolic control). However a second study was then conducted with a larger sample (Hampson, et al., 1995) with a similar pattern of results although this time beliefs concerning cause and treatment effectiveness significantly predicted glycosylated haemoglobin levels.

No studies to date have explored illness representations amongst IDDM young adults with diabetes. This may be important as a study by Brownlee-Duffeck, et al., (1987) based upon the health belief model found differences between young and old adults, with only the latter showing a correlation between perceived benefits of adherence and self care activities. Further research is also needed to explore emotional as well as

cognitive factors influencing treatment adherence because studies have indicated that emotional well-being may also impact upon self care activities (e.g. Hentinen & Kyngas, 1996; Goldston et al., 1994; Hanson et al., 1997).

In a recent publication Horne (1997) has also drawn attention to the importance of medication representations as it is feasible that a person with diabetes not only thinks about whether the illness warrants treatment but also whether insulin treatment is appropriate. Therefore a better understanding of the interplay between representations of illness, medication representation and treatment adherence might contribute to the future development of the SRM.

Horne (1997) has drawn upon literature which suggests that people have preconceptions or schema about medicine in general. For example, studies have revealed that people hold different views on medication including, a) a positive view focusing upon the beneficial effects of medication, b) a negative view perceiving medication as a form of poison producing unwanted side effects and c) a dual nature view of medicines which carry the potential for harm as well as benefit (Fallsberg, 1991).

The negative views about medication have also been found to focus around a number of themes including the risk of dependence or addiction (Conrad, 1985), fears about the long term side effects, beliefs that the body should be given a drug free rest period (Morgan & Watkins, 1988) and fears of medications being poison or unnatural (Fallsberg, 1991). Natural remedies were also seen as safer than "unnatural" medicine and the dangerous aspects of medication were linked to their chemical/unnatural origins (Conrad, 1985). People are also thought to have specific concerns about their medications weighing up the necessities of their treatment against fears concerning the potential harm of long term use.

Horne & Weinman (in press) set out to investigate the structure and prevalence of medication beliefs in a systematic way. They interviewed adults from three diagnostic groups including diabetes (n=99), chronic asthma (n=78) and haemodialysis (n=47) and generated a number of statements which represented common lay beliefs about medications. These beliefs were then separated into two questionnaires focusing upon medications in general (BMQ-General) and specific medicines prescribed for a particular illness (BMQ-Specific). These were then tested for reliability and validity.

The application of these questionnaires has revealed that people hold complex representations with firm beliefs about the necessity of medication balanced against concerns about the safety and disruptive effects of taking medication (Horne, 1997). Furthermore the interaction between general and specific beliefs was so strong that the author suggested that the focus should now be on the assessment of beliefs related to a specific illness rather than more general views.

Preliminary findings with a sample of adults with diabetes also suggested that specific medication beliefs are related to illness representations (identity & timeline) and treatment adherence (Horne, 1997) However only a brief non-standardised self-report adherence measure (focusing purely upon insulin use) was used so the results remain speculative. Furthermore, no research has examined this relationships amongst young adults with IDDM diabetes.

### **1.5 Rationale for the Current Study**

From the literature reviewed it would appear that young adults with diabetes may have problems in adhering to their treatment regimes. Furthermore very little research has examined why such problems are so prevalent in the younger population. Within health psychology the SRM provides an overarching cognitive framework from

which clinical interventions may be derived. However few studies have focused upon the applicability of this model within a diabetic population and none have focused upon the relationship between illness representations, medication beliefs, quality of life and treatment adherence amongst young adults with insulin dependent diabetes. Nor has current research considered the clinical value of this theory. Therefore the aim of this study is to explore these relationships and examine the potential value of the SRM for clinical interventions with this population.

### **1.6 Aims**

- 1 To provide data on adherence to diabetic treatment regime within a young adult sample age 17-30 years.
2. To examine whether younger people in the sample (aged 17-21 years) differ from "older" young adults (aged 23-30 years) in terms of treatment adherence.
- 3 To explore whether there is a relationship between self reported treatment adherence and metabolic control within both age groups 17-21 years and 23-30 years.
- 4 To provide data on the content of illness representations, medicine beliefs and quality of life factors within a young adult population aged 17-30 and to examine whether there are any differences between age groups (17-21 years and 23-30 years).
- 5 To assess the relative importance of the contributions of illness representations and medicine representations upon treatment adherence within both age groups 17-21 and 23-30 years.

- 6 To explore the relationship between self reported treatment adherence and perceived quality of life within both age groups 17-21 and 23-30 years.

### **1.7 Hypotheses**

1. Self reported measures of non adherence to treatment will be positively associated with poorer glycaemic control (one-tailed hypothesis).
2. Age groups will differ on measures of a) illness representations b) medicine beliefs, c) quality of life factors and c) treatment adherence (two-tailed hypothesis).
3. Illness representations will be related to treatment adherence (two-tailed hypothesis).
4. Medicine beliefs will be related to treatment adherence (two-tailed hypothesis).
5. There will be a relationship between treatment adherence and perceived quality of life (two-tailed hypothesis).



## **2. METHOD**

### **2.1 Ethical Approval**

Ethical approval was gained for the study and a copy of the letters from the four ethics committees consulted are included in Appendix 1.

### **2.2 Design**

The study was based upon a quantitative approach and employed a between group analysis to examine differences between young adults aged 17-22 years and those aged 23-30 years. A within group correlational design was also used to examine the relationship between illness perceptions, medication beliefs, perceived quality of life and adherence to treatment regimes.

A number of demographic factors such as gender, recruitment areas (affluent and non affluent) were controlled in order to ensure that any significant differences between groups were not due to the effect of these factors.

### **2.3 Participants**

The participants were recruited from four young adult clinics within hospitals in the South of England. The age inclusion criterion was 17-30 years which reflected the age range within the young adult clinics.

The participants included seventy-six people with insulin dependent diabetes of whom thirty-three participants were men and forty-two were women. From this sample thirty-seven participants were within the age range 17-21 years (mean 18

years; standard deviation 1.50) and thirty-nine fell within the age range 23-30 years (mean 27 years; standard deviation 2.08). As no participants aged 22 years attended the clinics at the time of data collection the younger age range was 17-21 years.

All participants had been diagnosed with diabetes for more than a year with a range from 1 to 28 years (mean ten years). Newly diagnosed diabetics and pregnant women were excluded as this would have had a direct effect on self care activities and diabetes control.

## **2.4 Demographic Information**

An information sheet outlining the study (appendix 2) and a background information sheet (appendix 3) provided demographic data including age, gender, ethnicity, educational levels, occupation, marital status, duration of diabetes, number of hospital admissions in the preceding year (& length of stay), type of insulin used, number of injections and dosages. In addition the researcher sought permission from participants to access their blood test results (HbA1c) which were routinely taken during their out-patient appointments.

## **2.5 Questionnaires**

### **2.5.1. Illness Perception Questionnaire (IPQ)** (Weinman, Petrie, Moss-Morris & Home, 1995).

This self report questionnaire consisted of thirty-eight items developed to assess individuals' illness representations (appendix 4) It contained five sub-scales that assessed the five components including *identity, consequences, control/cure, timeline and cause*.

The IPQ has been used for a variety of illnesses and has been specially adapted for diabetes research. It has been standardised on a number of large studies including a

diabetic population and has established psychometric properties with internal sub-scale consistency ranging from 0.71 to 0.81 (Weinman & Horne, 1995). Test-retest reliability coefficients for the sub-class ranged from 0.49 to 0.84 at one month and 0.33 to 0.66 at three months, which was significant ( $p < .01$ ).

The first twelve questions within the IPQ focused upon physical symptoms to form the illness identity sub-scale. These symptoms included pain, nausea, breathlessness, weight loss, fatigue, stiff joints, sore eyes, headaches, upset stomach, sleep difficulties, dizziness and loss of strength. Participants were asked to rate the frequency of these symptoms on a three point scale from "all the time " to "never." The resulting scores (ranging from 0 = Never to 3= all the time) were then summed to give a weighted illness identity (score range, 0-36).

The remaining twenty-three statements included ten items concerning the *cause* of diabetes; three items examining the perceived *time line* of diabetes, nine items relating to the perceived *cause* of diabetes, five items to the perceived degree of *control* over/or cure of their diabetes and four items regarding the perceived *consequences* of diabetes.

The researcher liased with the authors of the questionnaires and added a further three items to the *consequences* dimension including the statements " having diabetes prevents me from getting the best out of myself " ; "having diabetes has a bad effect on my close relationships"; and "having diabetes reduces my career options".

Participants were asked to rate the degree to which they agreed or disagreed with each statement for each item on a five point Likert scale ( `strongly agree` to `strongly disagree` ). The scores allocated to each statement ranged from one to five. For the majority of statements "strongly agree" was allocated five points and "strongly

disagree" one point. However for four statements (IP11, IP16, IP17 & IP23) the scoring was reversed.

Following reverse scoring for relevant statements the sum of scores for each of the *consequences*, *control/cure* and *time-line* scales were totalled and divided by the number of items in that sub-scale. In contrast the items relating to the *cause* sub-scale were scored individually as each item represents a specific causal belief (Weinman et al., 1996). Thus nine individual cause scores were obtained. To summarise the IPQ measure yielded five measures:-

1. Weighted illness identity score ranging from zero to thirty-six, a higher score indicating a greater illness identity.
2. Illness consequence score from one to five with higher scores indicating a greater perceived illness consequence
3. Illness control/cure from one to five with higher scores indicating a greater perceived control over and cure of illness
4. Illness timeline score ranging from one to five with higher scores indicating longer perceived timeline or duration of illness
5. Illness cause scores each ranging from one to five with a higher score indicating a stronger belief in causative dimensions including germ or virus, diet, pollution, hereditary, stress, own behaviour, poor medical care and state of mind.

### 2.5.2. Medications Belief Questionnaire, (appendix 5) Horne & Weinman, (in press)

This original questionnaire comprises of ten statements including beliefs about the necessity and efficacy of insulin (*specific-necessity*) and concerns about the harmful effects of insulin (*specific-concerns*). These items were examined within a pooled sample of over five hundred people including diabetic participants (n=99). A principle components analysis revealed that people organise their ideas about medicines into coherent themes including concerns and necessity beliefs. These components were found to be stable across different illness groups. In addition the internal consistency using Chronbach's Alpha ranged from 0.55 to 0.86 (Horne & Weinman, in press; Horne, 1997).

Test-retest reliability was conducted on the asthma group within a two week interval. The range of correlations from 0.66 to 0.77 were all significant ( $p < .01$ ) indicating the test-retest reliability as being within acceptable limits.

The researcher added a further seven statements to the concerns construct and these were derived from discussions with the author of the questionnaire, a review of literature and informal discussions with young adults with diabetes. With the additional statements the questionnaire consisted of seventeen statements and it was planned to explore the new statements using item analysis.

The questionnaire involved asking participants to rate their degree of agreement with each statement on a 5-point Likert scale (strongly agree to strongly disagree). The statements were organised around the two main constructs (*specific-necessary*; *specific-concerns*). Agreement with the statement received a higher score (e.g. 5 points for strongly agree; 1 point for strongly disagree). The statements were categorised as follows and the six statements added by the researcher are starred:-

### **Specific-Necessity**

My health in the future will depend on my insulin  
My health at present depends on my insulin  
My life would be impossible without my medicines  
Without my insulin I would be very ill  
My medicines protect me from becoming worse

### **Specific-Concerns**

Having to take my medicines worries me  
I sometimes worry about the long-term effects of my medicine  
I sometimes worry about becoming too dependent on my medicines  
My medicines are a mystery to me  
My medicines disrupt my life  
I worry that insulin will effect my weight\*  
Insulin does me more harm than good\*  
Insulin gives me unpleasant side-effects\*  
I sometimes worry that insulin will cause a hypo\*  
Having insulin interferes with my social life\*  
I find injecting insulin painful\*  
My insulin might become less effective if it was used regularly\*

The scores for statements within each component were added and divided by the number of items. The measures yielded from the medications beliefs questionnaire were as follows:-

1. Specific-Necessary score from one to five with the higher score indicating the greater perceived necessity of insulin.
2. Specific-Concern Score from one to five with the higher score indicating greater perceived concerns about using insulin

### **2.5.3. Short Form 36 Health Survey Questionnaire (SF-36)** (Ware, Snow, Kosinski & Gandek, 1993).

The SF-36 (appendix 6) has been vigorously tested for its reliability and validity (Jenkinson, Layte, Wright, & Coulter, 1996). Internal reliability tests have shown that items within dimensions are highly correlated (Brazier, Harper, Jones, O'Cathain, Thomas, Usherwood & Westlake, 1992) and alpha coefficients range from 0.73 for

social functioning to 0.96 for role limitation, physical, emotional and vitality (Wright, Harwood & Coulter, 1992).

The questionnaire consists of thirty-six items measuring the following nine health components (the item numbers are in brackets) including *physical functioning* (3a to 3j), *role limitations due to physical health problems* (4a to 4d), *role limitations due to emotional problems* (5a to 5c) *social functioning* (6, 9j) *mental health* (9b, 9c, 9d, 9f, 9h), *energy/vitality* (9a, 9e, 9g, 9i), *bodily pain* (7 &8), *general health* (1, 10a to 10d) and *change in health* (2).

The sub-scales are either forced choice "yes" or "no", (role limitations due to emotional and physical problems) or Likert scales ranging from three points (physical functioning), five points (change in health, general health perception and one of the social functioning and pain sub-scales) to six points (mental health, energy/vitality and the remaining social functioning and pain sub-scales). The higher the score the better the perceived health status.

#### **2.5.4. Summary of Diabetes Self-Care Activities** (Toobert & Glasgow, 1994)

This questionnaire (appendix 7) consisted of twelve items designed to measure the frequency of completing different treatment regime activities over the preceding seven days including *diet (the amount and type of food)*, *exercise*, *glucose test* and *insulin* use. The authors suggest that each of these regime components should be considered separately due to their relative independence of one another (Glasgow, McCaul, & Shafter, 1987).

The questionnaire has been standardised on three studies (Glasgow, Toobert, Riddle, Donnelly, Mitchell & Calder 1989a; Glasgow, Toobert, Mitchell, Donnelly, & Calder 1989; Glasgow, Toobert, Hampson, Brown, Lewinsohn & Donnelly, 1992). It has

established psychometric properties with internal consistency generally exceeding an inter-item correlation of above .5 for its sub-scales including , *diet*, *exercise* and *glucose tests*. The sub-scale examining use of *insulin* was not analysed because it lacked sensitivity as self-reported adherence to medication was high (Glasgow et al., 1989).

Test-retest reliability coefficients for sub-scales (excluding insulin use) ranged from .43 to .58 at six months follow-up suggesting a moderate degree of consistency. In addition participants had received treatment during the interval between assessments, therefore these correlations represent a mixture of stability of behaviour and response to intervention. The questionnaire also demonstrated moderate concurrent validity as correlation's between scores on tests measuring the same trait by different measures (including interview, three day food diary, dietary history, blood glucose monitoring form) were within an acceptable range (e.g.  $r = -.51$ ,  $p < 0.01$ ).

The researcher had some concerns about the internal reliability of the scales being less than .7 therefore to ensure that the best adherence measure available was used she personally contacted prominent researchers in the field of diabetes including Hanson, Glasgow (both in U.S.A) and Hampson (University of Surrey). They all reported that the Summary of Diabetes Self Care Activities Scale was the best measure available. In addition Bradley (1994) recommended this questionnaire in her "Handbook of Diabetes" book which included a chapter by Toobert & Glasgow (1994) detailing its construction and validity.

The American based questionnaire was piloted with six British participants and a few additions were made which will be highlighted below. The twelve items on the questionnaire were divided into the four regime sub-scales:- Adherence to diet was measured by five items. The first item asked "How often did you follow your recommended diet over the last seven days?". The second item asked for the



percentage of time the respondent successfully limited calories as recommended for diabetes control. The next three diet items are concerned with the percentage of meals which included high fibre foods, high fat foods or sweets and desserts.

Exercise was defined both in terms of absolute activity (number of exercise sessions lasting at least twenty minutes) and adherence (percentage of time the respondents exercised the amount suggested by their doctor). The pilot revealed that some participants became stuck on this item as they could not recall any recommendations concerning exercise. In America there appeared to be more emphasis upon exercise and therefore an additional response scale in respect of 'no exercise recommended' was added with this British population.

The two items concerning glucose testing were examined in terms of the number of tests performed in the past seven days as well as the percentage of this activity recommended by the doctor which was actually performed. Finally the original questionnaire included two items of medication (one of which was excluded as it was concerned with oral medication). Due to the unknown validity of the remaining item concerning insulin injection it was felt permissible to alter the scale (from a four point to five point Likert scale) so that it corresponded to the same categories as the glucose items above it.

The pilot revealed that participants had difficulty in quantifying adherence in terms of percentages. To avoid any confusion the researcher added additional guidelines under the percentages (e.g. **100% all of them 75% most of them; 50% about half** etc.) to help participants process the information.

The items were all based upon a 5-7 point Likert scale with higher scores allocated to greater adherence. The raw scores for each regime component were converted to standard scores having a mean of zero and a standard deviation of one. These

standardised scores were then averaged to form a composite score for each regime behaviour. The purpose of this procedure was to give items with differing scales equal weighting.

#### **2.5.5. Insulin Adherence Measure**

This was devised by the researcher for the purpose of the current study (appendix 8), as the existing insulin measure within the Self Care Activities Questionnaire was limited to one item with unknown validity. The researcher drew upon the Reported Adherence Measure (Horne, 1997) which consisted of three items to assess adherence to insulin in relation to forgetting, altering and missing doses. Despite this scales high internal consistency (Cronbach's Alpha =0.84) one of the items concerning altering doses of medication lacked face validity. This was because the introduction of the nova pens and fast acting insulin has meant that altering insulin doses according to glucose tests, food intake and exercise is not necessarily non adherent behaviour (and is actively encouraged by some diabetes nurses). Thus in agreement with the author it was decided to replace the altering insulin doses item with " I take my insulin exactly as advised by the doctor". A further four items concerning use of insulin were also added giving a total of seven items.

The insulin items were based upon a five point Likert scale with a higher score indicating non-adherence to medication. Each participant's total score was divided by seven to give an average adherence score ranging from 1 to 5.

An additional separate item was also included within the questionnaire concerning using insulin to help control weight. This item was initially based upon a five point Likert scale (never to always) and then converted to nominal data, including categorisation according to whether participants used insulin to control weight (sometimes, often, always = category 2) or not (rarely, never = category 1)

## **2.6 Summary of measures yielded and used in the study**

### **a. Background Information**

Age groups were divided; Age group one included participants aged 17-21 years and age group two included those aged 23-30 years. Background information included gender, ethnicity, marital status, educational qualifications, age of diabetes onset (duration of diabetes), number of hospital admissions in past year and length of stay (days), type of insulin, and number of insulin injections per day.

### **b. Haemoglobin Blood Test Results (HbA1c)**

### **c. Illness Perception Questionnaire**

- Symptom scores for each of the following: pain, nausea, breathlessness, weight loss, fatigue, stiff joints, sore eyes, headaches, upset stomach, sleep difficulties, dizziness and loss of strength.
- Weighted illness identity scores ranging from 0-36 (high scores indicated increased symptom frequency)
- Illness consequence score ranging from one to five (high score indicating greater perceived consequences of diabetes)
- Illness control/cure score ranging from one to five (high score indicating greater perception of control over diabetes).
- Illness timeline scores ranging from one to five (high scores indicating greater perceived timeline/duration of diabetes).

- Illness cause score one to five for each of the following: germ/virus, diet, pollution, heredity, chance, stress, own behaviour, caused by other people, poor medical care and emotional state of mind. High scores indicate greater belief in factor as causative.

**d. Medications Belief Questionnaire**

- Specific-Necessity score one to five with higher scores indicating greater perceived necessity of insulin
- Specific-Concern score of one to five with higher scores indicating greater perceived concerns about using insulin

**e. Quality of Life Measure: SF-36**

- Nine quality of life areas including, physical functioning, role limitations due to physical health problems, role limitations due to emotional problems, social functioning, mental health, bodily pain, general health, and change in health.

Each quality of life area was assigned a score ranging from 0-100, with a higher score indicating enhanced quality of life

**f. Summary of Diabetes Self-Care Activities**

- Four separate regime components including diet, exercise, glucose tests and insulin use items. Each item converted to z scores and divided by the number of items within each regime components with a positive standard deviation indicating greater adherence to treatment.

**g. Insulin Adherence Measure**

- Insulin score of one to five (higher scores greater non adherence to insulin treatment)
- Weight item - including category 1 = not using insulin to control weight and category 2 = using insulin to control weight

**2.7 Procedure**

The research was conducted within diabetes out-patients' clinics over a six month period. The clinics were based in four hospital sites covering both affluent and deprived catchment areas. Firstly the researcher met with the consultants and diabetes nurses to present and discuss the research proposal. Permission was then sought to conduct the research from appropriate ethic's committees and trust managers.

The questionnaires chosen for the research were then piloted with six participants and as a consequence additional instructions were included within the Self Care Activities Questionnaire as previously discussed.

The participants were recruited from the young adult out-patient clinics. The researcher was able to attend all the nine clinics within two of the hospital sites. Within these clinics it was arranged that before the researcher spoke to potential participants a member of staff would seek their permission to be approached. In addition an information sheet outlining the project was given (ref appendix 2) and a verbal explanation. The response rate was very high with ninety attenders to the clinic agreeing to participate. However, the DNA rate to the out-patients clinics varied from five to fifty percent.

The researcher was available to answer any questions about the project, although all participants reported the information sheet to be comprehensive enough. The confidentiality of the project was emphasised as well as the voluntary nature of their participation. Participants were also asked whether the researcher could access their blood test results (HbA1c) taken during clinic's appointment as part of their routine check-up.

The researcher then gave participants five questionnaires to fill in whilst in the waiting room. The questionnaires were given in random order (counterbalanced) to control for fatigue effect, and they took approximately twenty minutes to fill in. For those wishing to complete the questionnaires at home (n=10) a stamped address envelope was given (all were returned).

Within two hospital sites where the researcher was unable to be present (due to the timing of the clinics) a delegated nurse explained the project to participants and gave them the questionnaires to complete. The confidentiality of the project was emphasised and an envelope was given which could either be left in a research posting box at the clinic or taken home to post.

At the end of the questionnaire the participants were asked whether they would be willing to be contacted for a further interview as part of a second phase of the research project planned for the Autumn of 1998. They were also asked whether they would like a copy of the "first phase" outlined within this dissertation.

## **2.8 Statistical Analysis**

The study generated a mixture of ordinal, nominal and interval data. Nominal data included gender, age group (17-21 and 22-30 years), marital status, education and hospital admissions.

Interval data included, illness perceptions, medication beliefs, treatment adherence and quality of life measures. To determine the suitability of parametric analysis Levenes Test of homogeneity of variance was used. The data was also statistically analysed to assess normal distribution (Kolmogorov-Smimov) and plotted (histograms, & scatter plots). Unfortunately the data were found not to be normally distributed and therefore a non parametric analysis was deemed most appropriate (see appendix 9 for examples of histograms).

The analysis was divided into six stages

**Stage 1.** To establish the internal reliability of the measures which were developed or adapted for the study using Cronbach Alpha Statistics.

**Stage 2** Descriptive statistics were produced for demographic variables, self reported treatment adherence measures and haemoglobin blood test results.

**Stage 3** Spearman's Coefficients were used to explore whether there was a relationship between self-reported treatment adherence measures and metabolic control (HBA1c) within both age groups.

**Stage 4** The relationship between the insulin adherence measure and the insulin item within the self-care activities questionnaire was explored to assess their concurrent validity.

**Stage 5** Mann-Whitney U between group analysis test was performed to determine whether there were differences between age groups on illness representations, medication beliefs, quality of life factors, and treatment adherence.

**Stage 6** Spearman's Co-efficients were used for both age groups to determine the relationship between treatment adherence measures and three areas: illness representations, medication beliefs and quality of life factors.

All analyses were carried out using the statistical package for social science for windows, version, 6.1 (SPSS Inc, 1993). In view of the number of correlations used in the study it was decided to set a more stringent significant level of  $P < 0.01$ . A one tailed hypothesis was used for the univariate tests of association between metabolic control and self-reported adherence measures. This was because the direction of association was predicted based upon biological evidence i.e less insulin injected or high sugar intake would raise rather than lower blood glucose levels.

The remaining statistical analyses were based upon two tailed hypotheses.



### **3. RESULTS**

The results are presented in the following order:

- 3.1.** Cronbach Alpha internal reliability analysis of measures developed or adapted for this study.
- 3.2** Descriptive statistics for each age group including demographic variables, self reported treatment adherence and haemoglobin blood glucose test results.
- 3.3** Univariate tests of association between metabolic control and self-reported adherence measures within both age groups.
- 3.4** Univariate test of association between self reported insulin adherence measures.
- 3.5** Results of comparative tests (Mann-Whitney U) between age groups
- 3.6** Univariate tests of association for within age group 17-21 years and 23-30 years for variables including:-
  - Spearman's correlation between demographic indices and treatment adherence measures within both age groups.
  - Spearman's correlation between illness representations and treatment adherence within both age groups.
  - Spearman's correlation between medication beliefs and treatment adherence measures within both age groups.
  - Spearman's correlation between quality of life factors and treatment adherence measures within both age groups.

All significant levels are quoted at the  $p < 0.01$  levels one or two tailed.

### 3.1 Reliability of Measures

The results of the reliability analysis from the Illness Perception Questionnaire, Medication Beliefs Measure and Insulin Adherence Measure are presented in Table 1.

Table 1. Reliability analysis for Illness Representation Questionnaire, Medication Beliefs Measure, and Insulin Adherence Measure.

	Cronbach Alpha
<b>Illness Perception Questionnaire</b>	
Illness Identity	0.7305
Control/Cure	0.3197
Timeline	0.7004
Consequences	0.7787
<b>Medication Beliefs Questionnaire</b>	
Necessity	0.7114
Concerns	0.7824
<b>Insulin Medication Adherence Questionnaire</b>	0.7631

The measures showed an acceptable level of internal reliability apart from the control/cure scale within the Illness Perception Questionnaire which was excluded from the study.

### 3.2 Descriptive Statistics for Demographic variables

The samples' demographic characteristics are summarised in Table 2. The sample included a higher numbers of females within both groups and there were differences between the groups on marital status and educational status. This may have reflected the different developmental life stages, particularly as many of the participants in the younger group (N=15) were single and still in formal education.

Due to a high number of students within the sample it was not possible to use educational status to assess material deprivation as the academic potential of students

remained unknown. However approximately equal numbers of participants within both groups were recruited from affluent and non affluent hospital site catchment areas as measured by Jarman Indices (Jarman, 1991). This minimised the risk of material deprivation acting as a confounding variable in the comparison of age groups. Nevertheless this was not a perfect measure particularly as the London Hospital situated within a deprived inner city area had a broader catchment area including extra contractual referrals.

**Table 2 Demographic Characteristics of Participants**

	<b>Group 1</b>	<b>Group 2</b>
<b>Age Range</b>	<b>17-21 years</b>	<b>23-30 years</b>
<b>Number of Participants</b>	<b>37</b>	<b>39</b>
<b>Gender (male: female)</b>	<b>15:21</b>	<b>18:21</b>
<b>Marital Status:-</b>		
Single	36	22
Co-habiting/married	1	17
<b>Ethnicity</b>		
European	34	39
Afro Caribbean	2	
Asian	1	
<b>Educational Qualifications</b>		
None	2	2
GCSE's	19	12
A'Levels	16	5
Under Graduate Degree		13
Post Graduate Degree		6
<b>Years with Diabetes - range</b>	<b>1-17 years</b>	<b>1- 28 years</b>
mean	8.94 (4.45)	13.41 (8.25)
<b>Number of Hospital Admissions due to Diabetes in the Past Year</b>		
None	31	37
One	6	2
<b>Recruitment Site</b>		
Affluent area	17	17
Non affluent area	20	22

### **3.2.1 Descriptive Statistics for Self Reported Treatment Adherence**

The self-report treatment adherence measures revealed that a significant proportion of young adults in both groups were struggling to adhere to their treatment regimes. To illustrate this participants' responses to a selection of items within the self reported measures will be given for each treatment component as follows:-

#### **a) Glucose tests**

Within the Self Care Activity Questionnaire only 40 percent of young adults (n =15) aged 17-21 years reported to having tested their glucose every day in the previous seven days. A further 13 percent (n = 5) had tested their glucose most days, 33 percent (n =11) had only tested it on some of the days and 16 percent (n = 6) had not tested their glucose at all. This contrasted with higher levels of adherence amongst those aged 23-30 years with 69 percent (n = 27) reporting to have tested their glucose every day. A further eight percent (n = 4) reported to have done their glucose test on most of the past seven days, thirteen percent (n=5) on some of the days and only eight percent (n = 3) within this age group admitted to have not tested their glucose at all.

#### **b) Insulin Use**

Within the Self Care Activity Questionnaire 21 percent (n = 8) of 17-21 years and 15 percent (n=6) of 23-30 year olds admitted to having not taken all of their recommended insulin injections in the previous seven days (range 50-75 percent of recommended injections). In addition, within the Insulin Adherence Measure 27 percent (3 males: 9 females) in the younger age group reported to have altered insulin to help control their weight (sometimes, often or always). In contrast within the older group 19 percent (4 males: 4 females) reported that they altered insulin to help control

their weight. A further three participants reported to having only rarely altered their insulin for this purpose.

The Insulin Adherence Measure assessing general use of insulin was also highly associated with the insulin item in the Self Care Activities Questionnaire. This demonstrated that the measures showed good convergent reliability. Spearman's correlation also revealed a significant negative relationship between altering insulin to help control weight and the no. of recommended insulin injections used in the past week. This suggested that some participants were allowing their blood glucose levels to be raised in order to lose weight (see table 3).

**Table 3 : Spearmans Correlation between Insulin Adherence Measure and Self Care Activities Questionnaire**

	Self Care Activities Questionnaire			
	No. of insulin injections	Glucose testing	Diet	Exercise
<b>Group 1 (17-21 years)</b>				
<b>Insulin Adherence Questionnaire</b>				
Insulin	<b>r = -.675**</b>	r = -.156	r = -.285	r = .083
	p = .000	p = .258	p = .026	p = .485
Altering insulin to control weight	<b>r = -.358**</b>	r = -.047	r = .014	r = -.070
	p = .001	p = .785	p = .937	p = .679
<b>Group 2 (23-30 years)</b>				
Insulin	<b>r = -.519**</b>	<b>r = -.417**</b>	r = .112	r = -.282
	p = .000	p = .008	p = .497	p = .097
Altering Insulin to control weight	<b>r = -.408**</b>	r = -.074	r = -.071	r = .120
	p = .010	p = .656	p = .669	p = .485

\*\*significance level  $p < .01$

### c) Diet

The Self Care Activities Questionnaire also revealed that adherence to diet was relatively poor with only 51 percent of participants aged 17-21 years reporting having usually or always adhered to the recommended diet for healthy eating for diabetes

over the previous seven days. This contrasted to 72 percent within the age group 23-30 years who felt that they were adhering to their diets.

Twenty four percent of participants (n = 9) aged 17-21 years also reported that between 50 to 100 percent of their meals had included high sugar foods or drinks. A further 54 percent (n=20) had included such foods within 25 percent of their meals and only 22 percent (n=8) had avoided such foods altogether.

This contrasted to the older group (age 23-30) with only seven percent (n=3) of participants admitting to having included sweets and desserts in 50 percent of their meals over the past seven days, and a further 56 percent (n=22) having included such foods in 25 percent of their meals, and 36 percent (n=14) avoided such foods altogether.

#### **d) Exercise**

Within the exercise items on the Self Care Activity Questionnaire there was a broad range of reported physical activity (additional to daily tasks) within both groups. Seventy-eight percent within the younger group and 71 percent within the older group reported to have performed additional exercise at least twice during the past seven days. However, 40 percent of 17-21 year olds and 33 percent of 23-30 year olds reported to have received no advice from their doctor concerning exercise. Therefore the item exploring doctors' recommendations on exercise had to be omitted from further data analysis.

### 3.2.3 Descriptive Statistics for Haemoglobin Blood Glucose Levels

Finally physiological measures of glycaemic control within age groups revealed a high number of participants with raised blood glucose levels (see Table 4).

Table 4: Haemoglobin Blood Test Results Showing the Range of Glucose Control Amongst Participants

	Number of participants	
	(Percentages)	
	Group 1 (17-21 years)	Group 2 (23-30 years)
<b>Haemoglobin blood test results</b>		
Tight control - HbA1c range 5.4 - 6.9 m/l	8 (25.8%)	8 (24.2%)
Moderate control - HbA1c range 7.1 -7.9 m/l	4 (12.9%)	9 (26.5%)
Poor control - HbA1c range 8.0 - 8.9 m/l	7 (22.6%)	5 (14.7%)
Very poor control HbA1c range - 9.0 - 14.1 m/l	12 (38.7%)	12 (35.3%)
missing data	*6	*5

### 3.3 Univariate Tests of Association Between Metabolic Control and Self Reported Treatment Adherence Measures.

The relationship between physiological measures of glycaemic control and self reported measures was explored using Spearman's Correlations. No direct relationship was found within the 17-21 year old group although within the age group 23-30 years insulin use within both adherence measures were nearing a positive association with glycaemic control.

**Table: 5 Spearmans Correlation between HbA1c and Self Reported Adherence Measures. (one tailed hypothesis)**

	Haemoglobin Blood Test Results (HbA1c)	
	Group 1 (17-21 years)	Group 2 (23-30 years)
<b>Insulin Adherence Questionnaire</b>		
Insulin	r = .142	r = .329
	p = .223	p = .031
Altering insulin to control weight	r = .128	r = .361
	p = .246	p = .019
<b>Self Care Activities Questionnaire</b>		
Diet	r = .218	r = -.039
	p = .120	p = .414
Exercise	r = -.146	r = .182
	p = .216	p = .168
Glucose	r = -.152	r = -.158
	p = .207	p = .189
No. of recommended insulin injections	r = .033	r = -.352
	p = .430	p = .022

### **3.4. Results of Comparative Tests (Mann-Whitney) Between Age Groups.**

A non parametric Mann-Whitney U test explored differences between groups on demographic indices, illness representations, medication beliefs, quality of life and treatment adherence. As can be seen from Table 6 and 7, there were no significant differences between groups at the set level of .01. However the consequence scale within the Illness Perception Scale was nearing significance ( $p < .02$ ) with the older group perceiving greater consequences of diabetes upon their life.

A significant difference was also found between groups within self reported adherence measures. The younger adults (17-21) reported greater non adherence to glucose tests and diet as measured by the Self Care Activities Questionnaire (see table 6). Due to differences between groups on these measures it was decided that the age groups should be kept separate in further analysis.



**Table 6: Mann-Whitney U Between Group Analysis for IPO & Medication Beliefs**

		Mean Rank	Median	Range		z score	Sig
				Min	Max		
<b>Illness Perceptions</b>							
<b>Identity</b>							
	group 1	38.17	6.00	0.00	15.0	- 0.26	0.79
	group 2	36.87	6.00	0.00	14.0		
<b>Consequences</b>							
	group 1	32.53	2.70	1.20	4.50	-2.30	0.02
	group 2	44.17	3.00	2.00	4.40		
<b>Timeline</b>							
	group 1	35.38	5.00	2.33	5.00	1.34	0.18
	group 2	41.46	5.00	2.33	5.00		
<b>Cause:-</b>							
<b>Germ/virus</b>							
	group 1	33.01	2.00	1.00	5.00	- 2.17	0.03
	group 2	43.71	3.00	1.00	5.00		
<b>Diet</b>							
	group 1	38.39	1.00	1.00	4.00	- 0.05	0.96
	group 2	38.6	2.00	1.00	5.00		
<b>Pollution</b>							
	group 1	38.72	1.00	1.00	4.00	- 0.09	0.93
	group 2	38.29	1.00	1.00	4.00		
<b>Heredity</b>							
	group 1	37.42	2.00	1.00	5.00	- 0.43	0.67
	group 2	39.53	3.00	1.00	5.00		
<b>Chance</b>							
	group 1	39.38	3.00	1.00	5.00	- 0.75	- 0.45
	group 2	35.72	3.00	1.00	5.00		
<b>Stress</b>							
	group 1	37.89	2.00	1.00	5.00	- 0.16	0.88
	group 2	37.13	2.00	1.00	4.00		
<b>Other People</b>							
	group 1	39.04	1.00	1.00	5.00	- 0.47	0.64
	group 2	36.99	1.00	1.00	4.00		
<b>Own Behaviour</b>							
	group 1	38.27	1.00	1.00	3.00	- 0.10	0.92
	group 2	38.72	1.00	1.00	5.00		
<b>Poor Medical Care</b>							
	group 1	43.05	2.00	1.00	3.00	-2.00	- 0.05
	group 2	34.18	1.00	1.00	3.00		
<b>State of Mind</b>							
	group 1	37.56	1.00	1.00	4.00	-0.20	0.84
	group 2	38.41	1.00	1.00	3.00		
<b>Medication Beliefs</b>							
<b>Necessity</b>							
	group 1	36.86	4.40	2.80	5.00	- 0.44	0.66
	group 2	39.05	4.40	3.00	5.00		
<b>Concerns</b>							
	group 1	35.15	2.18	1.18	3.45	-1.29	0.20
	group 2	41.68	2.36	1.09	3.45		

**Table 7: Mann-Whitney U Between Group Analysis on Quality of Life Measures**

	<b>Mean Rank</b>	<b>Median</b>	<b>Range</b>		<b>z score</b>	<b>Sig</b>
			<b>Min</b>	<b>Max</b>		
<b>Quality of Live</b>						
<b>Physical Function</b>						
group 1	40.01	100.00	25.00	100.00	- 0.63	0.53
group 2	37.06	95.00	75.00	100.00		
<b>Role Limit/Physical</b>						
group 1	39.46	100.00	0.00	100.00	- 0.49	0.62
group 2	37.59	100.00	0.00	100.00		
<b>Role Limit/Emotional</b>						
group 1	38.03	100.00	0.00	100.00	- 0.01	0.99
group 2	37.97	100.00	0.00	100.00		
<b>Social Function</b>						
group 1	39.49	88.89	33.33	100.00	- 0.59	0.55
group 2	36.63	88.89	22.22	100.00		
<b>Mental Health</b>						
group 1	39.64	68.00	28.00	92.00	- 0.44	0.66
group 2	37.42	68.00	32.00	92.00		
<b>Energy/Vitality</b>						
group 1	38.07	65.00	20.00	95.00	- 0.03	0.98
group 2	37.93	60.00	10.00	95.00		
<b>Pain</b>						
group 1	38.28	88.89	0.00	100.00	- 0.11	0.91
group 2	37.74	88.89	11.11	100.00		
<b>General Health Perception</b>						
group 1	38.05	67.00	25.00	100.00	- 0.17	0.86
group 2	38.92	67.00	20.00	90.00		
<b>Change in Health</b>						
group 1	42.04	50.00	25.00	100.00	-1.51	0.13
group 2	35.14	50.00	25.00	100.00		

**Table 8: Mann-Whitney U Between Group Analysis on Treatment Adherence Measures**

		Mean Rank	Median	Range		z score	Sig
				Min	Max		
<b>Insulin Adher Measure</b>							
<b>Insulin</b>							
	group 1	35.15	1.29	1.00	3.29	0.44	0.66
	group 2	41.68	1.29	1.00	2.86		
<b>weight control</b>							
	group 1	39.30	1	1	2	-0.65	0.52
	group 2	37.74	1	1	2		
<b>Self Care Activities Quest</b>							
<b>Diet</b>							
	group 1	31.28	-0.22	-1.65	1.15	-2.78	0.01**
	group 2	45.35	0.45	-1.67	1.15		
<b>Exercise</b>							
	group 1	38.68	0.25	-1.15	2.18	-0.69	0.49
	group 2	35.28	-0.20	-1.15	2.18		
<b>Glucose Tests</b>							
	group 1	31.14	-0.19	-1.74	0.92	-2.90	0.00**
	group 2	45.49	0.78	-1.74	1.36		
<b>No. Insulin Injections</b>							
	group 1	37.23	0.46	-3.46	0.46	-0.73	0.47
	group 2	39.71	0.46	-3.46	0.46		
<b>HbA1c</b>							
	group 1	34.66	8.70	5.4	14.1	-0.90	0.37
	group 2	30.47	7.90	4.9	12.4		

\*\* significant p<.01

### 3.5 Univariate Tests of Association Within Age Groups between Independent Variables and Treatment Adherence Measures.

#### a) Demographic Variables

Table 9 shows that for the younger age group only there was an association between number of years with diabetes and adherence to insulin injections i.e those with more years of having diabetes were significantly less adherent to their insulin treatment.

**Table: 9 Spearmans Correlation between Demographic Indices and Treatment Adherence Measures within Age Groups 17-21 years and 23-30 years**

	HbA1c	Insulin Adherence		Summary of Self Care Activities			
		Measure		Diet	Exercise	Glucose	No. Insulin injections
		Insulin	Weight				
<b>Group 1 (17-22yrs)</b>							
<b>Demographic</b>							
Gender	r = .051 p = .784	r = .084 p = .622	r = .219 p = .192	r = .191 p = .258	r = -.160 p = .344	r = -.159 p = .347	r = .180 p = .287
Education	r = -.194 p = .194	r = -.091 p = .593	r = -.090 p = .597	r = .313 p = .059	r = .011 p = .974	r = .017 p = .920	r = -.125 p = .462
No. years with diabetes	r = -.065 p = .734	r = .157 p = .361	r = .020 p = .906	r = -.196 p = .252	r = .111 p = .518	r = .121 p = .483	r = -.451** p = .006
<b>Group 2 (23-30 yrs)</b>							
Gender	r = .354* p = .043	r = .205 p = .210	r = -.045 p = .784	r = -.069 p = .677	r = .070 p = .685	r = -.347* p = .031	r = -.255 p = .117
Education	r = -.041 p = .822	r = .069 p = .543	r = .053 p = .753	r = .116 p = .488	r = .075 p = .670	r = -.021 p = .900	r = -.095 p = .569
No. years with diabetes	r = .242 p = .189	r = .329 p = .270	r = .160 p = .345	r = -.106 p = .532	r = .008 p = .962	r = -.120 p = .478	r = -.233 p = .165

\*\* Significant P<.01

**b) Illness Representations**

Contrary to the hypothesis no relationship was found between illness representations and treatment adherence within age group 17-21 years (table 10) or within age group 23-30 years.

**Table 10: Spearman's Correlation between Illness Representation and Treatment Adherence Measures**

	HbA1c	Insulin Adherence		Summary of Self Care Activities			
		Measure		Diet	Exercise	Glucose	No. Insulin injections
		Insulin	Weight				
<b>Group 1 (17-21yrs)</b>							
<b>Illness Perception</b>							
Identity	r = .347 p = .060	r = .277 p = .102	r = .108 p = .529	r = -.064 p = .709	r = .033 p = .851	r = -.170 p = .320	r = -.225 p = .187
Timeline	r = -.067 p = .719	r = .093 p = .583	r = .017 p = .918	r = -.107 p = .528	r = -.147 p = .385	r = -.110 p = .517	r = -.132 p = .438
Consequences	r = .093 p = .621	r = .137 p = .420	r = .130 p = .443	r = -.069 p = .683	r = .022 p = .947	r = .196 p = .920	r = -.170 p = .462
<b>Cause -</b>							
Germ/virus	r = -.144 p = .441	r = -.027 p = .873	r = -.031 p = .855	r = -.094 p = .581	r = .029 p = .863	r = .332* p = .045	r = -.127 p = .453
Diet	r = .001 p = .995	r = .019 p = .911	r = .149 p = .377	r = -.052 p = .761	r = .083 p = .626	r = -.122 p = .470	r = -.222 p = .187
Pollution	r = -.145 p = .435	r = -.221 p = .188	r = -.054 p = .751	r = .090 p = .597	r = .128 p = .450	r = .206 p = .221	r = .068 p = .690
Heredity	r = -.386* p = .032	r = -.300 p = .071	r = -.006 p = .974	r = .272 p = .104	r = .071 p = .674	r = .128 p = .451	r = .396* p = .015
Chance	r = .227 p = .229	r = .028 p = .871	r = -.192 p = .261	r = -.153 p = .374	r = .031 p = .859	r = -.073 p = .674	r = -.242 p = .154
Stress	r = -.175 p = .355	r = -.066 p = .704	r = -.033 p = .850	r = .100 p = .563	r = .040 p = .816	r = .289 p = .087	r = -.095 p = .583
Other people	r = -.009 p = .960	r = -.079 p = .644	r = -.120 p = .479	r = .286 p = .086	r = .199 p = .237	r = -.074 p = .663	r = .102 p = .549
Own Behaviour	r = .040 p = .829	r = -.109 p = .520	r = .158 p = .351	r = .153 p = .367	r = .103 p = .543	r = .016 p = .927	r = -.059 p = .727
Poor medical care	r = .020 p = .914	r = -.116 p = .493	r = .033 p = .847	r = .319 p = .055	r = .153 p = .368	r = .072 p = .672	r = -.051 p = .766
State of mind	r = -.015 p = .937	r = -.119 p = .491	r = -.080 p = .641	r = .094 p = .586	r = .140 p = .415	r = .046 p = .789	r = .040 p = .819

**Table: 11 Spearman's Correlation between Illness Representation and Treatment Adherence Measures within Age Groups 23-30 years**

	HbA1c	Insulin Adherence		Summary of Self Care Activities			
		Measure		Diet	Exercise	Glucose	No. Insulin injections
		Insulin	Weight				
<b>Group 2 (23-30yrs)</b>							
<b>Illness Perceptions</b>							
Identity	r = .195 p = .285	r = .035 p = .835	r = .302 p = .066	r = -.372 p = .021	r = -.165 p = .335	r = -.310 p = .058	r = .004 p = .983
Timeline	r = -.300 p = .090	r = -.180 p = .274	r = -.213 p = .192	r = -.068 p = .683	r = -.027 p = .875	r = .085 p = .605	r = .257 p = .114
Consequences	r = .114 p = .527	r = .362 p = .806	r = .162 p = .324	r = -.114 p = .491	r = -.125 p = .466	r = -.084 p = .611	r = -.230 p = .159
<b>Cause -</b>							
Germ/virus	r = .075 p = .679	r = .053 p = .750	r = -.032 p = .847	r = -.108 p = .511	r = -.035 p = .840	r = -.243 p = .136	r = -.246 p = .132
Diet	r = -.338 p = .054	r = -.266 p = .102	r = .160 p = .331	r = -.303 p = .061	r = -.125 p = .466	r = -.072 p = .664	r = -.056 p = .737
Pollution	r = -.141 p = .434	r = .010 p = .954	r = .172 p = .296	r = .186 p = .257	r = -.207 p = .225	r = -.116 p = .482	r = -.059 p = .721
Heredity	r = .129 p = .474	r = -.141 p = .392	r = .081 p = .624	r = .125 p = .448	r = .173 p = .314	r = .175 p = .286	r = .077 p = .643
Chance	r = -.032 p = .861	r = .041 p = .809	r = -.039 p = .814	r = -.312 p = .057	r = -.296 p = .079	r = -.296 p = .071	r = .109 p = .514
Stress	r = -.237 p = .191	r = .075 p = .655	r = .003 p = .986	r = .031 p = .852	r = -.258 p = .129	r = -.237 p = .153	r = -.063 p = .706
Other People	r = .052 p = .777	r = .063 p = .707	r = .292 p = .075	r = -.020 p = .907	r = -.109 p = .526	r = .020 p = .903	r = -.129 p = .440
Own Behaviour	r = -.299 p = .091	r = -.183 p = .264	r = .055 p = .739	r = -.186 p = .257	r = -.265 p = .119	r = .010 p = .951	r = -.042 p = .797
Poor medical Care	r = -.103 p = .570	r = -.025 p = .881	r = .020 p = .905	r = -.005 p = .978	r = -.234 p = .170	r = -.113 p = .495	r = -.188 p = .253
State of mind	r = -.206 p = .250	r = .028 p = .863	r = .104 p = .528	r = -.047 p = .776	r = -.167 p = .331	r = -.028 p = .863	r = -.086 p = .604

**c) Medication Beliefs**

The Spearman's correlation revealed one significant relationship between medication beliefs and insulin adherence measures within the younger age group only. This involved a negative relationship between using insulin to help control weight and beliefs about the necessity of insulin medication. Within the older age group there

was a trend towards high concerns about insulin and using insulin to help control weight although this was only significant at a  $p < .05$  (see table 11).

**Table: 12 Spearman's Correlation between Medication and Treatment Adherence Measures within Age Groups 17-21 years and 23-30 years.**

	HbA1c	Insulin Adherence		Summary of Self Care Activities			
		Measure					
		Insulin	Weight	Diet	Exercise	Glucose	No. Insulin injections
<b>Group 1 (17-21 yrs)</b>							
<b>Medication Beliefs</b>							
Necessity	$r = -.119$ $p = .530$	$r = -.144$ $p = .401$	$r = -.451^{**}$ $p = .006$	$r = -.093$ $p = .590$	$r = -.200$ $p = .243$	$r = .077$ $p = .657$	$r = .165$ $p = .335$
Concerns	$r = .128$ $p = .494$	$r = .033$ $p = .845$	$r = .141$ $p = .406$	$r = .028$ $p = .869$	$r = -.090$ $p = .598$	$r = .106$ $p = .534$	$r = -.153$ $p = .367$
<b>Group 2 (23-30yrs)</b>							
<b>Necessity</b>							
	$r = -.229$ $p = .200$	$r = -.012$ $p = .940$	$r = .016$ $p = .924$	$r = -.018$ $p = .914$	$r = .140$ $p = .415$	$r = .073$ $p = .657$	$r = -.006$ $p = .970$
<b>Concerns</b>							
	$r = .169$ $p = .347$	$r = .136$ $p = .408$	$r = .316$ $p = .050$	$r = -.356$ $p = .026$	$r = -.115$ $p = .530$	$r = -.309$ $p = .055$	$r = -.247$ $p = .130$

\*\* Significant  $p < .01$

#### d) Quality of Life Measures

Finally quality of life factors appeared to be associated with HbA1c and self reported insulin adherence measures. Table 13 (overleaf) shows for the younger age group (17-21 years) raised haemoglobin blood glucose levels were associated with lower levels of social functioning. The Insulin Adherence Measure also revealed an association between higher levels of non adherence and reduced quality of life in areas relating to role limitation due to physical problems, social functioning, mental health, energy and vitality and general health perceptions.

For the young age group only general health perceptions were associated with the insulin item within the Self Care Activities Questionnaire although an association

with energy/vitality and reported role limitations due to physical problems was nearing significance ( $p < .02$ ).

**Table 13: Spearmans Correlation between Quality of Life and Treatment Adherence Measures within Age Groups 17-21 years and 23-30 years.**

	HbA1c	Insulin Adherence		Summary of Self Care Activities			
		Insulin	Weight	Diet	Exercise	Glucose	No. Insulin injections
<b>Group 1 (17-21yrs)</b>							
<b>Quality of Life</b>							
Physical Function	r = -.139 p = .457	r = -.021 p = .900	r = -.045 p = .793	r = .234 p = .164	r = .180 p = .288	r = .204 p = .225	r = -.018 p = .914
Role limit/physical	r = -.130 p = .486	r = -.449** p = .005	r = -.181 p = .285	r = .048* p = .048	r = -.151 p = .371	r = .066 p = .698	r = .378 p = .021
Role limit/emotional	r = -.249 p = .184	r = -.361 p = .031	r = .052 p = .763	r = -.054 p = .755	r = -.083 p = .629	r = .233 p = .172	r = .284 p = .093
Social Functioning	r = -.535** p = .002	r = -.417** p = .010	r = -.171 p = .319	r = .078 p = .650	r = .330* p = .049	r = .152 p = .375	r = .069 p = .691
Mental Health	r = -.087 p = .642	r = -.436** p = .007	r = -.264 p = .115	r = .230 p = .172	r = -.126 p = .456	r = .042 p = .807	r = .245 p = .144
Energy/Vitality	r = -.128 p = .492	r = -.489** p = .002	r = -.155 p = .360	r = .335* p = .043	r = -.036 p = .834	r = .196 p = .246	r = .367 p = .025
Pain	r = -.207 p = .272	r = -.397 p = .016	r = -.332 p = .048	r = -.054 p = .754	r = -.122 p = .478	r = .093 p = .589	r = .188 p = .273
General Health Percept	r = -.177 p = .340	r = -.547** p = .000	r = -.198 p = .214	r = .319 p = .055	r = .088 p = .603	r = .211 p = .209	r = .501** p = .002
Change in Health	r = .216 p = .243	r = -.338 p = .041	r = -.255 p = .127	r = .318 p = .055	r = .053 p = .755	r = .184 p = .275	r = .261 p = .119
<b>Group 2 (23-30yrs)</b>							
Physical Function	r = -.396 p = .022	r = .087 p = .599	r = -.036 p = .826	r = .194 p = .237	r = .140 p = .415	r = .136 p = .410	r = -.087 p = .598
Role limit/Physical	r = -.349 p = .047	r = -.226 p = .167	r = .054 p = .742	r = .283 p = .081	r = .230 p = .176	r = .155 p = .347	r = .118 p = .475
Role limit/Emotional	r = -.328 p = .063	r = -.281 p = .084	r = -.269 p = .097	r = .188 p = .251	r = .034 p = .846	r = .239 p = .142	r = .413** p = .009
Social Function	r = -.527** p = .002	r = -.297 p = .076	r = -.361 p = .024	r = .242 p = .138	r = .090 p = .603	r = .309 p = .056	r = .458** p = .003
Mental Health	r = -.498** p = .003	r = -.321 p = .047	r = -.257 p = .115	r = .131 p = .426	r = .012 p = .946	r = .190 p = .246	r = .317 p = .050
Energy/Vitality	r = -.372 p = .036	r = -.147 p = .379	r = -.058 p = .732	r = .264 p = .109	r = .158 p = .365	r = .354 p = .029	r = .348 p = .032
Pain	r = -.403 p = .020	r = -.208 p = .204	r = -.320 p = .047	r = .149 p = .365	r = .127 p = .459	r = .397 p = .012	r = .244 p = .134
General Health Percept	r = -.451** p = .008	r = -.239 p = .143	r = -.233 p = .153	r = .017 p = .919	r = .089 p = .608	r = .238 p = .145	r = .323 p = .045
Change in Health	r = .125 p = .488	r = -.198 p = .226	r = -.159 p = .333	r = .133 p = .419	r = -.069 p = .688	r = .114 p = .491	r = -.007 p = .967

\*\* Significant  $p < .01$



For the older age group a slightly different pattern emerged as haemoglobin levels were related to mental health and general health perceptions as well as social functioning. In contrast to the younger group there were no significant relationships between the Insulin Adherence Measure. However the insulin item in the Self Care Activities Questionnaire was related to two quality of life factors (including role limitation due to emotional problems and social functioning).

Within the older age group an association between using insulin to control weight and lower levels of social functioning was also nearing the desired significance level ( $p < .02$ ).

For both age groups there were no significant relationships between quality of life measure and adherence to diet, exercise or glucose testing. For the older age group only there was a trend towards an association between glucose testing and two quality of life measures including energy/vitality ( $p < .029$ ) and pain ( $p < .012$ ).

## 4. DISCUSSION

### 4.1 Discussion of Method

The response rate of 90 percent was high for this type of design although the sample consisted of only those who attended the diabetes clinic. For practical and ethical reasons it was not possible to contact the high numbers of young adults (5 to 50 percent) who did not attend their clinical appointments (DNA).

Those who attended their clinical appointments may have been more highly motivated and more adherent to their treatment regimes as previous research has suggested (e.g. Hammersley et al., 1985). However, participants within this study did report higher levels of treatment non-adherence as compared to other studies (e.g. Dunnings, 1995).

This study strove towards methodological rigour although there are a number of problems inherent within the research design. For example a major disadvantage of using closed-ended questions was that people may have understood the questions differently (Sheatsley, 1983). For example additional open-ended questions may have given participants the opportunity to qualify their answers. However, this was weighed against the importance of keeping the research within reasonable time constraints so to reduce fatigue effects for participants (which was also controlled for by counterbalancing questionnaire presentation). In addition the advantage of only including close-end questions was that they were more easily comparable across respondents. Furthermore, as previously mentioned, follow-up interviews were being planned for later this year.

Participants' responses to questionnaire items may have also been subjected to social desirability effects (Crowne & Marlowe, 1960, 1964) i.e as participants understood the necessity of their treatments it was possible that their responses were tempered by what they felt should be the correct answer rather than reality. This was partly addressed through the inclusion of physiological measures of glycaemic control although as previously discussed this may not have been a perfect measure of treatment adherence.

There was also the potential of increased social desirability effects within the two hospital sites where diabetes nurses rather than the researcher gave out the questionnaires. However, to reduce this effect, confidentiality was emphasised and participants were instructed to seal their completed questionnaires in envelopes which were returned directly to the researcher.

#### **4.1.2 Measurement Issues**

The high number of students in the sample led to problems in determining material deprivation through occupational status or educational qualifications. It was possible that material deprivation could have been an intervening variable in the comparison of age groups. Nevertheless participants within both age ranges were recruited from each hospital site and this may have reduced the chance of such differences between groups. On reflection participants' home postal codes may have been a more accurate way of assessing and controlling the effects of material deprivation.

The issue of reliability and validity of measures was a major consideration in the study and great efforts were made to use standardised measures. It proved difficult to obtain a good measure of self reported adherence to insulin as even within the Self Care Activities Questionnaire the insulin item had not been subjected to rigorous

analysis (Toobert & Glasgow, 1993). Furthermore, the poor face validity of the Insulin Adherence Measure (Horne, 1997) meant that adjustments and additions to this measure were needed.

When redesigning the Insulin Adherence Measure much thought went into its construction. To reduce the acquiescence effects (i.e a tendency to agree rather than disagree with items) reversal items were included (which is a way of asking a similar question in an opposite way). This method may also have increased the inter-correlations between items therefore improving the scale's internal consistency. To increase the reliability of the questionnaire a five point response scale was used (Nummally, 1978). This did not avoid the potential problem with central tendency e.g. people tending to avoid the extreme end of scales although arguably a middle point was necessary to represent a genuine alternative judgement (Barker, Pistrang & Elliot, 1994).

The Internal reliability of the Insulin Adherence Measure was good (i.e Chronbach Alpha .78) suggesting that the items related well together. On reflection a multivariate statistical technique such as factor analysis could have been used to examine further the underlying dimensions within the questionnaire. It may also have been beneficial to administer the questionnaire twice to a sub-sample of participants in order to assess the measures test-retest reliability. However it was acknowledged that adherence behaviours naturally fluctuate over time.

The piloting of the Insulin Adherence Measure and consultation with medical professionals helped to ensure its face validity. Establishing criteria validity was more difficult because objective measures such as glycaemic control may not purely reflect treatment adherence. Nevertheless there did appear to be nearing a significant relationship between all of the insulin adherence measures and HbA1c but only for the

older age group. It is not known why this relationship was not found within the younger age group and this issue will be developed further in the general discussion.

The Insulin Adherence Measure also correlated well with the insulin item within the Self Care Activities Questionnaire which indicated good convergent validity. Furthermore, as anticipated (Toobert & Glasgow, 1993) it was not correlated with diet or exercise. This highlighted its discriminate validity. These findings also emphasised the need to evaluate different components of diabetes treatment separately.

The remaining questionnaires used within the study were standardised and additional items added to the consequence scale (within the IPQ) and the concern scale (within the Medication Belief Measure) appeared to improve their internal reliability.

Unfortunately the internal reliability of the control scale within the IPQ was poor (Chronbach Alpha .32) and therefore excluded. This was disappointing as it meant that the study was unable to measure this component within Illness Representations. However the poor performance of the control scale in this study and some others has prompted the authors to revise this scale before it is used in further research (this information was gathered from personal communication with Prof. Weinman).

#### **4.1.3. Statistical Issues**

The use of a non parametric analysis had the disadvantage of less statistical power as compared to parametric tests. However the advantages were that non parametric tests could be used on data which were not normally distributed and the analysis would have been less affected by the presence of any outliers within the data.

It was decided not to subject the data to further sophisticated analysis such as regression analysis as the sample size was felt to be too small. This was because there were five treatment adherence components (dependent variables) to separately analyse. Hence even if only independent variables significant at univariate level were entered a larger sample would be required (i.e at least five participants were needed for each independent variable entered per analysis). Furthermore there would have been the potential problem of only selecting significant variables as some variables at univariate level that were not significant may have been significant at multivariate level.

The set significance level ( $p < .01$ ) reduced the chance of type I errors (false positives) although inevitably this increased the chance of type II errors (false negatives). Nevertheless due to the high number of correlations used within the study a stringent probability level was more appropriate as one in hundred false positives may arise at  $p < .01$  level compared to one in twenty at  $p < .05$  level

It is also important to observe that the data yielded by many of the measures gave a relatively small range therefore large effects sizes would be required to detect significant results.

Finally the study was limited by its correlational design as a causal relationship could not be established. The variables may be causally related but because of the so-called third variable problem this connection could not be made e.g. there may be another variable not taken into account within a linear correlation which may explain the association between the observed relationship. This will be discussed further within the general discussion.

## **4.2 Aims & Hypothesis**

The purpose of this study was to explore treatment adherence amongst young adults with diabetes within two age groups. Furthermore it was to examine the relationship between treatment adherence and three independent variables including illness representations, medication beliefs and quality of life. Five hypotheses were generated and the discussion will focus on the main findings related to these.

### **4.2.1 Hypothesis One: Participants within age group 17-21 years olds will differ from age group 23-30 years on measures of treatment adherence**

Generally self reported treatment adherence within this young adult sample was variable and differences between age groups were revealed in relation to glucose testing and diet.

The younger age group reported to be lax in glucose testing with 60 percent admitting to having not tested their glucose levels every day. These levels of non adherence were higher than previous research has reported. For example Dunning's (1995) only found thirty-three percent not to be performing daily tests. However Dunning's (1995) sample included a broader age range (17-33 years) which may have obscured the higher rates of non adherence within the 17-21 year old age range. Indeed the older age group within this sample was comparable with Dunning's research as only 31 percent were not performing daily glucose tests.

Sixteen percent of participants in the younger age group, (compared to eight percent in the older age group) admitted to having not performed any glucose tests during the past week. This level of serious non adherence particularly within the younger age

group is also higher than previous research finding. For example McCaul et al., (1987) only revealed seven percent of young adults reporting such negligence.

This study has not explained the reason behind non adherence to glucose testing although Gonder-Frederick et al's., (1986) research concerning beliefs about glucose testing may be of relevance. Their research as previously discussed suggested that participants who do not perform glucose tests believe that they will be able to detect change in glucose levels through subjective physical symptoms (although this has been proved to be an unreliable indicator). However their research finding may not fully explain the discrepancies found between age groups within this study. Studies have yet to address factors such as the financial costs of obtaining glucose testing strips, the impact of glucose testing on life style or the potential emotional distress associated with observing a glucose test that reveals a too high or too low glucose level. During the piloting of the questionnaires one participant spoke of fears of long term medical complications which were provoked when faced with fluctuating glucose levels in spite of conscientious efforts to keep glucose levels within a safe range. Further research is required to explore whether such fears may lead to avoidance behaviours.

The younger age group also showed greater non adherence to diet with twenty-four percent reporting to having included high sugar foods or drinks with 50-100 percent of their meals. This compared to only seven percent within the older age range. Interestingly the researcher found that guidance on food intake appeared to differ between clinics and it appeared that further clarity was needed. For example within one clinic a diabetes nurse informed the researcher that diabetic patients could eat what they liked as long as insulin levels injected and exercise were adjusted appropriately. This contrasted to another nurse who emphasised the importance of adherence to a low sugar diet.



There also appeared to be some confusion amongst participants regarding how best to manage a complex treatment regime. For example whilst going through the questionnaire with one participant he explained how he adjusted his insulin doses according to food intake. His intentions were well meaning although his dangerously high blood glucose levels and developing medical eye complications suggested that he was not managing to control his diabetes within this more complex but more lenient diet regime. The staff within the clinic felt that he was being deliberately non adherent but the impression from the researcher was that he was confused as to how to manage his treatment. More research is required to explore the relationship between knowledge and self management of diabetes in the light of new methods of managing diabetes.

This study did not find significant differences between age groups on exercise or insulin use. Within the whole sample of young adults the percentage of participants (n=14) admitting to reducing the number of insulin injections was greater than other studies. For example, as previously discussed, Peveler et al., (1993) only found two percent of young adults reporting this type of non adherence compared to eighteen percent within the current sample.

In contrast Pelter et al., (1993) did report a similar finding concerning the use of insulin to help control weight i.e 33 percent of their participants reported to have altered insulin for weight control as compared to 26 percent within the current study. Nevertheless both Peveler et al., (1993) and Dunning (1995) found female participants predominately used insulin for weight control, whereas the current study suggests that some males (n=7) as well as females (n=13) engage in this activity.

Unfortunately this study does not explain why these participants manipulated insulin to control weight. However it would be of interest to explore the personal meaning

behind their actions. Indeed it was always envisaged that a second phase of this study would take place later in the Autumn of 1998.

**4.2.2. Hypothesis Two: Self reported treatment adherence measure will be positively associated with glycaemic control (HbA1c) within age groups 17-21 and 23-30 years.**

Haemoglobin blood test results did not reveal significant differences between groups and from the total sample of participants 47 percent had raised blood glucose levels. For the older age group all of the insulin measures were nearing significance within a logical direction, i.e those who took less insulin than recommended had raised blood sugar levels, which would have also achieved weight loss.

Within the younger group self reported measures were not significantly associated with haemoglobin blood test results. Research, as previously mentioned, has drawn attention to the direct influence of stress upon glycaemic control (e.g. Glasgow et al., 1986), although this may fail to explain the differences between age groups.

It could be suggested that the younger age group were more susceptible to a social desirability effect in their response to insulin items or alternatively the higher levels of non adherence to glucose testing may have had an indirect effect upon glycaemic control. In particular inaccuracies may arise if participants were adjusting insulin doses according to subjective information (Gonder-Frederick & Cox, 1991).

The lack of a direct relationship between glucose testing and glycaemic control could be due to the glucose measure lacking in sensitivity. For example, glucose items within the Self Care Activities Questionnaire only explored daily glucose testing, rather than multiple daily testing that would be required if insulin doses were to be adjusted. It would be of interest to ascertain whether a more sensitive measure

exploring the relationship between glucose testing and altering insulin doses would have produced a closer relationship with HbA1c.

**4.2.3. Hypothesis Three: Age groups 17-21 years will differ from age group 23-30 years on measures of a) illness representations b) medicine beliefs, and c) quality of life factors.**

The negative association between years of diabetes and insulin adherence within the younger age group was cause for concern. This highlights the need to investigate further underlying reasons why over time some younger adults may become more lax with their insulin regimes. However an air of caution is needed when reviewing this result due to the cross sectional nature of this study and the relatively small number of participants (n=8) reporting within the Self Care Activities Questionnaire to have missed out insulin injections. A larger longitudinal study may explore this association in greater depth.

The hypothesis concerning differences between groups on Illness Representations was not supported apart from a tendency ( $p < .02$ ) for the older group to perceive a greater consequence of diabetes. However within both groups there was broad range of responses in that some participants perceived low consequences whilst others perceived high consequences. Beliefs about the cause of diabetes also differed between participants although there were no significant age group differences.

Most participants perceived diabetes as having a long time-line. The one participant within the current sample who did disagree with a long time line also commented upon advances in medicine concerning potential pancreas transplants. Hampson et al., (1995) also found that the majority of participants believed that diabetes would last a long time which lead them to suggest that this item had limited value for distinguishing beliefs between participants.

The symptoms that participants were experiencing as part of their diabetes (illness Identity) were on relatively low (medium score 6). This highlighted the limited value of subjective information such as symptoms acting as a guide for insulin dose adjustments and glycaemic control.

There were also no significant differences between age groups concerning medication beliefs. Within the total sample participants on average believed that insulin was necessary and had low concerns regarding insulin treatment. There was however a range of responses with some participants holding weaker beliefs about the necessity of insulin treatment or stronger concerns about insulin use.

Finally concerning quality of life there were no significant differences between groups although the range of responses within each age group was very broad. Furthermore the median score within both age groups for mental health, energy and vitality, general health perception and perceived changes in health were well below optimum levels. This related to Tebbi et al's., (1990) research suggesting reduced quality of life amongst young adults with diabetes as compared with "healthy" peers.

#### **4.2.4. Hypothesis Four, Five & Six: Illness representations, Medication Beliefs and/or Quality of Life will be related to treatment adherence.**

Contrary to the hypothesis no significant relationship was found between illness representations and treatment adherence. However within the younger age groups there was an association between weaker beliefs concerning the necessity of insulin treatment and adjusting insulin to help control weight. This relationship was not found within the older age group although using insulin to control weight was nearing association with higher concerns about insulin ( $p < .05$ ). For the younger age group in particular there does appear to be an appraisal of insulin in the context of

manipulating insulin levels for reasons other than maintaining good glycaemic control. The theoretical implications of these findings will be discussed later.

Within both age groups there were significant relationships between quality of life factors, haemoglobin blood glucose levels and measures of insulin adherence although the pattern of this relationship did appear to differ between groups i.e more quality of life factors were directly associated with insulin use within the younger age group and haemoglobin levels within the older group. The reasons for this remain unknown apart from identifying age as an important third variable within the significant associations.

It was also important to observe that there were no significant relationships with quality of life and measures concerning altering insulin to help control weight, diet or exercise. For the older age group only energy/vitality and pain were nearing association in relation to glucose testing although such relationships failed to explain the widespread non adherence to glucose testing within the younger age group.

A causal relationship between quality of life factors, haemoglobin blood test results and Insulin Adherence cannot be deduced from this correlational design. There was a possibility that high blood glucose levels and/or non adherence to insulin have led to a reduction in quality of life. However, the lack of a direct relationship within this sample between symptoms (e.g. Illness Identity) and glycaemic control suggests that this may not be the case. It is also possible that reduced quality of life had impacted negatively on treatment adherence and/or increased stress levels leading to higher blood glucose levels.

### **4.3 Theoretical Implications**

This study has not provided full support for the Self Regulation Theory as illness representations did not appear to impact on management behaviours. Nevertheless caution is needed when reviewing the research findings as this study only tapped into four of the five illness representations due to measurement problems concerning perceptions of the control of diabetes. In addition the correlational non parametric design which included a relatively small sample would have reduced statistical power to detect associations. Furthermore it is possible that illness representation may link to other outcome measures apart from treatment adherence such as emotional well-being. This relationship has been found within a study involving participants with chronic fatigue syndrome (Moss Morris, Petrie & Weinman, 1996).

The self-regulatory model also described an interaction between illness perceptions and emotional representations although this is yet to be explored. It is possible that quality of life measures tapped into emotional representations which may have had a greater influence upon treatment adherence.

This study gave some marginal support for the proposal that cognitions about medications influence treatment adherence (Horne, 1997). Within the young age group there did appear to be an interplay between weighing up the necessity of insulin treatment and manipulating insulin for weight control. In terms of this theory (Horne, 1997) this relationship may have represented a rational decision making process concerning the necessity of insulin treatment which increased the vulnerability to misuse insulin for weight purposes. However an alternative explanation may have been that the underestimation of the necessity of treatment had arisen as a result of a defence against anxiety concerning the serious medical repercussions resulting from insulin misuse.

This study does not explain why there was no relationship between beliefs about the necessity of treatment and the weight item within the older age group. Neither has it provided insight into the underlying reasons why participants feel the need to change their body image. Other theoretical frameworks may need to be incorporated in order to understand this behaviour taking into account social pressures upon young people to strive towards a perfect body image as well as literature concerning eating disorders (Garner & Garfinkel, 1985). Further research is also needed to assess how the impact of a chronic condition such as diabetes may impact upon self perceptions and body image.

In the area of medication beliefs this study does not explain the lack of association between medication beliefs and general insulin use. One of the problems encountered in determining a relationship between general insulin use and medication beliefs was that a relatively small number of participants reported to be missing out insulin injections. It is possible that the statistical analysis may not have been powerful enough to detect significant associations within this small sub-sample.

Horne (1997) suggested that participants' beliefs about their treatments should be incorporated within the Self Regulatory Model. However this study focused purely upon beliefs concerning insulin use rather than glucose testing, diet and exercise. It may be important in the future to explore participants' beliefs concerning all aspects of their treatment especially glucose testing which appeared to be neglected amongst young adults aged 17-21 years.

The Self Regulatory Model also incorporated a "feedback loop" whereby the effectiveness of the management of diabetes was appraised and refined. This was not assessed within the study and could be of importance, particularly as adherence to treatment regimes may not always lead to good glycaemic control due to other

biological factors. Furthermore the model described "the self" as an over-riding factor and further research is required to explore the ways in which diabetes is incorporated into self-identity and how this may influence the management of diabetes.

#### **4.4 Implications for Further Research**

This study has focused narrowly upon a limited range of cognitions and as previously discussed more research is required to explore participants' belief systems in more depth before firm conclusions can be made. In particular beliefs concerning all aspects of diabetes treatments regimes need to be explored and more information gathered on young adults' perception of diabetes control. Once assessment measures such as the Illness Perception Questionnaire and Medication Beliefs Questionnaire are refined and tailored to a young adult populations a study involving a larger sample may be of value.

Currently little attention has been focused on emotional representations and other aspects outlined above within the Self Regulatory Model. The finding concerning perceptions of quality of life suggests that further research is required to study how this may relate to emotional representations and impact upon treatment adherence. Initially this may be achieved through a qualitative research design. An intervention study may also be of value to assess the causal relationships between treatment adherence and quality of life. For example, it could be evaluated as to whether a treatment programme designed to improve treatment adherence improved quality of life or vice versa.

Further research involving a longitudinal design is also required to explore age group differences which were found in relation to glucose testing and diet taking into account developmental differences. It would also be of interest to explore the



understanding of young adults and medical professionals regarding the best way to manage diabetes.

#### **4.5 Implication for Clinical Practice**

The implications for clinical practice are less clear than anticipated as the cognitive perceptions assessed did not appear to be associated with diabetes management.

These findings also related to the researcher's recent clinical experience in the field of health psychology where working within a purely cognitive-behavioural framework was felt to be far too restrictive in terms of understanding health behaviours.

The Self-Regulation Theory as a whole offers promise as a guide to therapeutic practice as it does incorporate components such as emotional representations, the impact of diabetes upon self identity as well as cognitions. However within the field of health psychology much more focus has been on cognitions rather than on the exploration of emotions which may be harder to measure objectively. Nevertheless from a clinical perspective this research highlights the need to explore in more depth with individuals how diabetes interacts with quality of life. This will inevitably require an understanding of how diabetes impacts at an emotional as well as at a cognitive level.

This study has also highlighted age group differences which emphasise the need to understand problems which young adults may be experiencing within a developmental context. Furthermore the high rates of reported insulin abuse in relation to weight control is clearly an important avenue to explore with both male and female young adults. It may be of value to liaise with dietitians to explore dietary regimes and provide young adults with alternative ways of weight control apart from insulin abuse. Furthermore for some individuals therapists may need to draw upon psychological literature on eating disorders (Garner, & Garfinkel, 1985).

The need to work within a psychological and as well as a medical framework has been emphasised in this study. Clinical psychologists' training involving a multi-theoretical framework has placed them in a prime position for therapeutic work amongst young adults with diabetes or supervision of nursing staff. However clinical psychology training does not equip the therapist with an in-depth knowledge of diabetes. This knowledge is also required to understand the emotional sequel to diabetes e.g. therapists need to be aware that as individuals become hypoglycaemic they may become disinhibited which may impact upon interpersonal relationships etc. Further specialist training could potentially be offered within the field of health psychology and this may be of value for clinical psychologists and other therapists who wish to work within this field.

Informal discussions with diabetes nurses and consultants gave the researcher the impression that the expertise from psychologists would be welcomed and that they are aware that diabetes can cause distress for their clients. However the question remains of how best to integrate clinical psychology within diabetes medical teams bearing in mind the potential funding problems and the scarcity of psychologists. A strong argument could be put forward for the development of specialist diabetes clinical psychologists who would connect into teams offering direct clinical work and supervision. If this was to be established it would be important to pilot such schemes and assess their value in terms of both medical (improved glycaemic control) and psychological gains (improved quality of life).

The finding also highlighted the need for further clarity on the best way to manage diabetes as there appeared to be differences amongst staff concerning recommendations on the number of glucose tests required, altering insulin doses and diet. In addition many young adults reported that they received no guidance on exercise.

The Control & Complications Trial (1993) appears to have influenced clinical practice as some young adults had been encouraged to alter their insulin levels according to food intake. However, within the trial participants altered insulin doses according to multiple glucose tests (four per day). They were also highly motivated and received monthly medical appointments. This contrasted to the young adults within this sample many of whom did not engage in daily glucose testing and did not have regular contact with medical professionals.

For some individuals with poor control it may be important to explore how they are managing their treatment regimes rather than automatically attributing this to deliberate non-adherence. For example individuals may be altering insulin levels as advised without performing sufficient glucose tests.

#### **4.6 Summary**

The study aimed to explore whether illness representations, medication beliefs and quality of life were associated with treatment adherence amongst young adults with diabetes. Whilst illness perceptions did not appear to be of significance, measures of quality of life were associated HbA1c and insulin adherence measures. In relation to the Self Regulatory Model (Leventhal, et al., 1984) it was suggested that quality of life may be related to emotional representations and further research is required in the understanding of the emotional sequel to diabetes.

Twenty participants within the study also reported that they use insulin to help control weight and medication beliefs were associated with this particularly within the younger age group. This suggested that cognitions about treatments alongside perceptions of body image should be explored within clinical interventions. The study also revealed difference between age group on glucose testing and diet suggesting that

further research is required to explore the impact of developmental issues on health care behaviours.

In conclusion this study has indicated the need to integrate psychological and medical understanding to encapsulate the variety of factors that influence young adults and treatment adherence behaviours.

## REFERENCES

- Ajzen, I. & Fishbein, M. (1980). Understanding Attitudes and Predicting Social Behaviour. Englewood Cliffs, NJ: Prentice Hall.
- Ajzen, I. (1985). From intentions to actions: a theory of planned behaviour. In Ed. J. Kuhl & J. Beckmann. Action Control: From Cognitions to Behaviour. Heidelberg: Springer-Verlag.
- Anderson, B.J., Auslander, W.F., Jung, K.C., Miller, J.P. and Santiago, J.V. (1990). Assessing family sharing of diabetes responsibility. Journal of Paediatric Psychology, 15 (4), 477-492.
- Anderson, S.A. (1990). 'Changes in parental adjustment and communication during the leaving-home transition'. Journal of Social and Personal Relationships, 7, pp. 47-68.
- Balfour, L., White, D.R., Schiffrin, A., Dougherty, G., & Dufresne, J. (1993). Dietary disinhibition, perceived stress, and glucose control in young, type 1 diabetic women. Health Psychology, 12, (1), 33-38.
- Barker, C., Pistrang, N., Shapiro, D.A., & Shaw, I. (1990). Coping and help-seeking in the UK adult population. British Journal of Clinical Psychology, 29, 271-285.
- Becker, M.H., & Maiman, L.A. (1975). Sociobehavioural determinants of compliance with health and medical care recommendations. Medical Care, 13, 10-23.
- Blos, P. (1962). On Adolescence: A Psychoanalytic Interpretation. New York: Free Press.
- Blos, P. (1967). "The second individuation process of adolescence". Psychoanalytic Study of the Child 22: 162-86.
- Bond, G.G., Aiken, L.S., & Somerville, S.C. (1992). The health belief model and adolescents with insulin-dependent diabetes mellitus. Health Psychology, 11, 190-198.

- Bradley, C. (1982). Psychophysiological aspects of the management of diabetes mellitus. International Journal of Mental Health, 11, 117-132.
- Bradley, C. (1994). Measures of perceived control of diabetes. In C. Bradley (Ed.), Handbook of Psychology and Diabetes, pp 291-331. Switzerland: Harwood Academic.
- Bradley, C., Lewis, K.S., Jennings, A.M., & Ward, J.D. (1990). Scales to measure perceived control developed specifically for people with tablet-treated diabetes. Diabetic Medicine, 7, 685-694.
- Brazier, J.E., Harper, R., Jones, N.M.B., O'Cathain, A., Thomas, K.J., Usherwood, T. & Westlake, L. (1992). Validating the SF-36 Health Questionnaire Health Survey Questionnaire: new outcome measure for primary care. British Medical Journal, 305, 160-164.
- Brownlee-Duffeck, M., Peterson, L., Simonds, J.F., Goldstein, D., Kilo, C., & Hoette, S. (1987). The role of health beliefs in the regimen adherence and metabolic control of adolescents and adults with diabetes mellitus. Journal of Consulting and Clinical Psychology, 55, 139-144.
- British Diabetic Association, (1995). Fact Sheet. London: BDA.
- Burroughs, T.E., Pontious, S.L., & Santiago, J.V. (1993). The relationship among six psychosocial domains, age, health care adherence, and metabolic control in adolescents with IDDM. The Diabetes Educator sep/oct 19, (5), 396-402.
- Coleman, J. (1980). The Nature of Adolescence. London: Methuen & Co. Ltd.
- Conrad, (1985). The meaning of medications: another look at compliance. Social Science and Medicine 20 (1), 29-37.
- Cox, D.J., Gonder-Frederick, L., Pohl, S., & Pennebaker, J.W. (1986). Diabetes. In K.A. Holdroyd, & T.L. Creer (Eds.). Self-management of Chronic Diseases, pp. 305-346. Orlando, Florida: Academic Press.
- Crowne, D.P., & Marlowe, D. (1964). The Approval Motive: Studies in Evaluative Dependency. New York: Wiley.

- Diabetes Control and Complications Trial Research Group. (1993). The effects of intensive treatment of diabetes on the development and progression of long term complications in insulin-dependent diabetes mellitus. New England Journal of Medicine, 329, 977-986.
- Dunbar-Jacob, J. & Schlenk, E.A. (1996). Treatment adherence and clinical outcome: can we make a difference? In (Eds) R.J. Resnick & R.H. Rozensky. Health Psychology Through the Life Span: Practice and Research Opportunities: chapter 21, pp 323-343. Washington, D.C: American Psychological Association.
- Dunn, S.M., & Turtle, J.R. (1981). The myth of the diabetic personality. Diabetes Care, 4, 640-646.
- Dunning, P.L. (1995). Young-adult perspective of Insulin-Dependent Diabetes. The Diabetes Educator, Vol 21 (1), 58-65.
- Edwards, C.R.W., Baird, J.D. and Toft, A. D. (1991). Endocrine and metabolic disease. In (Eds) C.R.W. Edwards, I.A.D. Bouchier. Davidson's Principles and Practice of Medicine, 16th edition; chapter 12, pp. 607-698. Edinburgh: Churchill Livingston.
- Eiser, C., Flynn, M., Green, E., Tavermans, T., Kirby, R., Sanderman, D., Tooke, J.E. (1993). Coming of age with diabetes: patients' views of a clinic for under 25 year olds. Diabetic Medicine, 5, 285-289.
- Epstein, L.H. & Cluss, P.A. (1982). A behavioural medicine perspective on adherence to long-term medical regimens. Journal of Consultant Clinical Psychology, 50, 993-1003.
- Erikson, E.H. (1963). Childhood and Society (2nd edn). New York: W.W. Norton & Co. Inc.
- Erikson, E.H. (1968). Identity, Youth, & Crisis. New York: W.W. Norton & Co. Inc.
- Fallsberg, M. (1991). Reflections on medicines and medication: a qualitative analysis among people with long-term drug regimens PhD Thesis. Sweden: Linkoping University.
- Garner, D.M., & Garfinkel, P.E. Handbook of Psychotherapy for Anorexia Nervosa and Bulimina. New York: Guildford Press.

- Glasgow, R.E., McCaul, K.D., & Schafter, L. (1986). Barriers to regimen adherence among persons with insulin-dependent diabetes mellitus. Health Psychology, 9, 503-515.
- Glasgow, R.E., McCaul, K.D., & Shafter, L.C. (1987). Self-care behaviours and glycemic control in Type I diabetes. Journal of Chronic Diseases, 40, 399-412.
- Glasgow, R.E., Toobert, D.J., Hampson, S.E., Brown, J.E., Lewinsohn, P.M., & Donnelly, J. (1992). Improving self-care among older patients with Type II diabetes: The "Sixty Something...." Study. Patient Education and Counselling, 19, 61-74.
- Glasgow, R.E., Toobert, D.J., Mitchell, D.L., Donnelly, J.E., & Calder, D.C. (1989). Nutrition education and social learning interventions for Type II diabetes. Diabetes Care, 12, 150-152.
- Glasgow, R.E., Toobert, D.J., Riddle, M., Donnelly, J., Mitchell, D.L., & Calder, D. (1989a). Diabetes-specific social learning variables and self-care behaviours among persons with Type II diabetes. Health Psychology, 8, 285-303.
- Goldston, D.B., Kovacs, M., Obrosky, S. & Lyengar, S. (1995). A longitudinal study of life events and metabolic control among youths with Insulin-Dependent Diabetes Mellitus. Health Psychology, Vol. 14, (5), 409-414.
- Gonder-Frederick, L.A., & Cox, D.J. (1990). Symptom perception, symptom beliefs, and blood glucose discrimination in the self treatment of Insulin Dependent Diabetes. In A. Skelton, & R.T.Croyle. Mental Representations in Health and Illness, pp 220 - 246. London:Kyngas, H., & Barlow, J. (1995). Diabetes: An Adolescent's Perspective. Journal of Advanced Nursing, 22, 941-947.
- Gonder-Frederick, L., & Cox, D.J. (1991). Symptom perception, symptom beliefs, and blood glucose discrimination in the self-treatment of insulin-dependent diabetes. In (Eds) J.A. Skelton, & R.T. Croyle. Mental Representations in Health and Illness, pp 220-246. New York: Springer-Verlag.
- Gonder-Frederick, L.A., & Cox, D.J., Pennebaker, J.W., & Bobbitt, S.A. (1986). Blood glucose symptom beliefs in Type 1 diabetic adults: Accuracy and implications. Health Psychology, 3, 327-341.
- Gordis, L. (1976). Methodological issues in the measurement of patient compliance. In Eds D.L. Sackett & R.B. Haynes. Compliance with Therapeutic Regimens. pp 51-68. Baltimore, MD: John Hopkins University Press.



- Hammersley, M.S., Holland, M.R., Walford, S., & Thorn, P.A. (1985). What happens to defaulters from a diabetic clinic? British Medical Journal, 291, 1330-1332.
- Hampson, S.E. (1997). Illness representations and the self-management of diabetes. In (Eds). Weinman, J, & Petrie, K. Perceptions of Illness and Treatment: Current Psychological Research and Applications. Switzerland: Harwood Academic.
- Hampson, S.E., Glasgow, R.E., & Toobert, D.J. (1990). Personal models of diabetes and their relation to self-care activities. Health Psychology, 9, 632-646.
- Hampson, S.E., Glasgow, R.E., & Foster, L.S. (1995). Personal models of diabetes among older adults: Relation to self-management and other variables. The Diabetes Educator, 21, 300-307.
- Hanestad, B.R., & Albrektsen, G. (1991). Quality of life, perceived difficulties adherence to a diabetes regimen and blood glucose control. Diabetes Medicine, 8, 759-764.
- Hanson, C.L., De Guire, M. J., Schinkel, A. M., Kolterman, O.G., Goodman, J.P., & Buckingham, B.A., (1996). Self-care behaviours in insulin dependent diabetes: Evaluative tools and their associations with glycemc control. Journal of Paediatric Psychology, 21, (4), 467-482.
- Hanson, C.L., Henggeler, S.W., & Burghen, G.A. (1997). Social competence and parental support as mediators of the link between stress and metabolic control in adolescents with insulin-dependent diabetes mellitus. Journal of Consulting and Clinical Psychology, 55, (4), 529-533.
- Hentinen, M., & Kyngas, H., (1996). Diabetic adolescents' compliance with health regimens and associated factors. International Journal of Nursing Studies, 33, (3), 325-337.
- Horne, R. (1997). Representations of medication and treatment: advances in theory and measurement. In (Ed), K. Petrie, & Weinman, J. (1997). Perceptions of Health and Illness: Current Research and Applications, pp. 155-187. London: Harwood Academic.
- Horne, R & Weinman, J. (1998) The beliefs about medicines questionnaire (BMQ): a new method for assessing beliefs about medicines. Psychology & Health, in press.

- Hurley, C.C., & Shea, C.A. (1992). Self-efficacy: A strategy for enhancing diabetes self-care. The Diabetes Educator, 18, 146-150.
- Jarman, B. (1991). General practice, the NHS review of social deprivation. British Journal of General Practice, 41, 76-9.
- Jenkinson, C., Layte, R., Coulter, A. & Wright, L. (1996). The U.K. SF-36: An Analysis and Interpretation Manual. Oxford: Health Service Research Unit.
- Johnson, S.B. (1984). Knowledge, attitudes, and behaviour: Correlates of health in childhood diabetes. Clinical Psychology Review, 4, 503-524.
- Johnson, S.B. (1988). Diabetes Mellitus in Childhood. In (Eds) D.K. Routh. Handbook of Paediatric Psychology, pp 9-31. London: Routledge.
- Kavangh, D.J., Gooley, S., & Wilson, P.H. (1993). Prediction of adherence and control of diabetes. Journal of Behavioural Medicine, 16, 509-522.
- Kinmonth, A.L. & Marteu, T.M. (1989). Doctors' beliefs and the management of insulin dependent diabetes: implication for shared care. Family Practice, 6, 193-198.
- Klein, B.E., Moss, S.E., & Klein, R. (1992). Use of cardiovascular disease medication and mortality in people with older onset diabetes. American Journal of Public Health, 82, 1142-1144.
- Koch.M.F & Molnar, G.P. (1979). Psychiatric aspects of patients with unstable diabetes mellitus. Psychosomatic Medicine, 36, 57-117.
- Kovacs, M., Goldston, D., Obrosky, D.S., & Lyengar, S. (1992). Prevalence and predictors of pervasive non-compliance with medical treatment among youths with insulin-dependent diabetes mellitus. Journal of American Academic child Adolescent Psychiatry 31(6), 1112-1119.
- Kovacs, M., Mukerji, P., Iyengar, S. & Drash, A. (1996). Psychiatric disorder and metabolic control among youths with IDDM. Diabetes Care, 19, (4), 318-323.
- Kyngas, H., & Hentinen, M.(1995). Meaning attached to compliance with self-care, and conditions for compliance among young diabetics. Journal of Advanced Nursing, 21, 729-736.
- Leventhal, H., Diefenbach, M., & Leventhal, E.A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. Cognitive Therapy and Research, 16 (2), 143-163.
- Leventhal, H., & Nerenz, D. (1985). Assessment of Illness Cognition. In P. Karoly (Ed.), Measurement Strategies in Health, pp.517-554. New York: Wiley.

- Leventhal, H., Nerenz, D., & Steele, D. (1984). Illness representations and coping with health threats. In (Eds) A. Baum & J. Singer. A Handbook of Psychology and Health, 4, 219-252. Hillsdale, NJ: Lawrence Erlbaum Associates.
- Levinson, D.J., Darrow, D.N., Klein, E.B., Levinson, M.H., and Mckee, B. (1978). The Seasons of a Man's Life. New York: A. A. Knopf.
- Lewis, K.S. & Bradley, C. (1994). Measures of diabetes-specific health beliefs. In C. Bradley (Eds). Handbook of Psychology and Diabetes, pp 247-289. London: Harwood Academic.
- Lipsett, L.F. (1980). Overview of diabetes mellitus. Behavioural Medicine Update, 2, 15-17.
- Lundman, B., Asplund, K & Norberg, A. (1990). Living with diabetes: perceptions of well-being. Research Nursing Health, 13, 255-262.
- McCaul, K.D., Glasgow, R.E., & Schafer, L.C. (1987). Diabetes regime behaviours. Predicting adherence. Medical Care, 25, 868-881.
- Morgan, M., & Watkins, C.J. (1988). Managing hypertension: beliefs and responses to medication among cultural groups. Sociology of Health and Illness 10,(4), 561-578.
- Moss Morris, R., Petrie, K., & Weinman, J. (1996). Functioning in chronic fatigue syndrome. Do illness perceptions play a regulatory role? British Journal of Health Psychology, 1, 15-25.
- Murawski, B.J., Chazan, M.B., Balodimos, M.C., & Ryan, J.R. (1979). Personality patterns in patient with diabetes mellitus of long duration. Diabetes, 19, 259-263.
- Newbrough, B.J., Simpkins, C.G., & Maurer, H. (1985). A family development approach to studying factors in the management and control of childhood diabetes. Diabetes CARE, 8, 83-92.
- Nunnally, J.C. (1978). Psychometric Theory (2nd edn.). New York: McGraw-Hill.

- Peveler, R.C., Davis, B.A., Mayou, R.A., Fairburn, C.G., & Mann, J.I. (1993). Self-care behaviour and blood glucose control of young adults with type 1 diabetes mellitus. Diabetic Medicine, 10, 74-80.
- Reichard, P., Nilsson, B. Y., & Rosenqvist, U. (1993). The effect of long-term intensified insulin treatment on the development of microvascular complication in diabetes mellitus. New England Journal of Medicine, 329, 304-309.
- Rosenstock, L.M. (1974). Historical origins of the health belief model. Health Education Monographs, 2, 328-335.
- Rotter, J. B. (1954). Social Learning and Clinical Psychology. Englewood Cliffs NJ: Prentice-Hall.
- Rotter, J.B. (1966). Generalised expectancies for internal versus external control of reinforcement. Psychological Monographs 80, (whole no. 609) 1-28.
- Sanazaro, P. (1985). A survey of patient satisfaction, knowledge and compliance. Western Journal of Medicine, 142, 703-705.
- Sheatsley, P.B. (1983). Questionnaire construction and item writing. In P.H. Rossi, J.D. Wright & A.B. Anderson (Eds.). Handbook of Survey Research. Orlando: Academic Press.
- Simmonds, J. 1976-1977. Psychiatric status of diabetic youth in good and poor control. International Journal of Psychiatry in Medicine, 7, 133-151.
- Stone, D. B. (1964). A study of the incidence and causes of poor control in patients with diabetes mellitus. American Journal of Medical Sciences, 241, 436-469.
- Swift, C.R., Seidman, F., & Stein, H. (1967). Adjustment problems in juvenile diabetes. Psychosomatic Medicine, 29, 55-58.
- Tebbi, C.K., Bromberg, C., Sills, I., Cukierman, J., Piedmonte, M. (1990). Vocational adjustment and general well-being of young adults with IDDM. Diabetes Care, 13 (2), 98 -103.
- Toobert, D.J. & Glasgow, R.E. (1994). Assessing diabetes self management: The summary of diabetes self-care activities questionnaire. In Lewis, K.S. &

- Bradley, C. Handbook of Psychology and Diabetes, pp 351-375. London: Harwood Academic.
- Turnquist, D.C., Harvey, J.H., & Anderson, B.L. (1988). Attributions and adjustment of life-threatening illness. British Journal of Clinical Psychology, 27, 55-65.
- Wallston, K.A., Wallston, B.S. & De Vellis, R. (1978). Development of the multidimensional health locus of control (MHLC) scales. Health Education Monographs, 6, 160-170.
- Ware, J.E., Snow, K.K., Kosinski, M.A. & Gandek, B. (1993). SF-36 Health Survey: Manual and Interpretation Guide. Boston: The Health Institute.
- Wasserman, D.H., & Zinman, D. (1994). Exercise in individuals with IDDM. Diabetes Care, 17, 924-937.
- Weibe, D.J., Alderfer, M.A., Palmer, S.C, Lindsay, R., & Jarrett, L. (1994). Behavioural self-regulation in adolescents with type 1 diabetes: negative affectivity and blood glucose symptom perception. Journal of Consulting and Clinical Psychology, 62, (6), 1204-1212.
- Weiner, M.F., & Skipper, F.P. (1979). Euglycemia: A psychological study. International Journal of Psychiatry in Medicine, 9, 281-287.
- Weinman, J., Petrie, K.J., Moss-Morris, R. & Horne, R. (1996). The illness perception questionnaire: a new method for assessing cognitive representations of illness. Psychology and Health, 11, 431-445.
- Williams, T.F., Martin, D.A., Hogan, M.D., Watkins, J.D., & Ellis, E.V. (1967). The clinical picture of diabetic control studied in four settings. American Journal of Public Health, 57, 441-451.
- Wilson, D.P., & Endres, R.K. (1986). Compliance with blood glucose monitoring in children with type 1 diabetes mellitus. Journal of Paediatrics, 108, 1022-1024.
- Wood, J.(1997). Coping with intercurrent infection. Diabetic Nursing, Issue 26, 11-13.
- Wright, L., Harwood, D. & Coulter, A. (1992). Health and Lifestyle in the Oxford Region. Oxford: Health Services Research Unit.

Wysocki, T., Hough, B.S., Ward, K.M., & Green, L.B. (1992). Diabetes mellitus in the transition to adulthood: Adjustment, self care and health status. Developmental and Behavioural Paediatrics, 13 (3), 194-201

Zimmerman, B.R. (1990). Non-insulin dependent (Type II) diabetes: Medical Overview. In C.S.Holmes (Ed.), Neuropsychological and Behavioural Aspects of Diabetes, pp. 177-183. New York: Springer-Verlag.

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Appendix 1  
Ethical Approval Letters





Preston Hall, Aylesford  
Kent ME20 7NJ  
Tel 01622 710161  
Fax 01622 719802  
Minicom 01622 713005

22 September 1997

Ms.  
4, Northfields  
Speldhurst  
TUNBRIDGE WELLS  
Kent, TN3 OPL

Dear

***AN INVESTIGATION TO EXAMINE THE IMPACT THAT ILLNESS REPRESENTATIONS HAVE UPON TREATMENT ADHERENCE AMONGST YOUNG ADULTS (AGED 17-25 YEARS) WITH INSULIN DEPENDENT DIABETES. FURTHERMORE TO EXPLORE HOW REPRESENTATIONS OF ILLNESS RELATE TO A PERSON'S SELF IDENTITY.***

***PROTOCOL NO. 43/97*** (Please quote in all correspondence)

At the meeting on Friday 12th September 1997, the Tunbridge Wells Local Research Ethics Committee reviewed your application form, together with the protocol for the project, Patient Information Sheet and Consent Form.

The members of the Committee present agreed that there is no objection on ethical grounds to the proposed study whose title is given at the head of this letter. I am therefore happy to give you our approval on the understanding that you will follow the protocol as agreed.

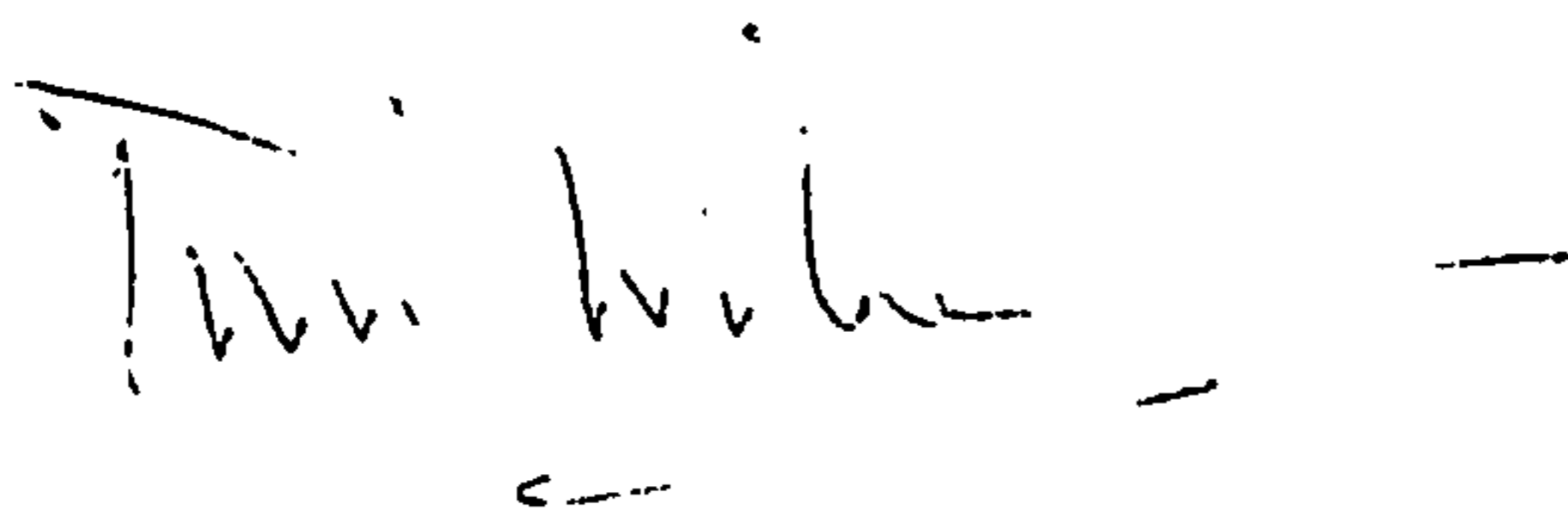
It is your responsibility as the researcher who made the application to notify the Local Research Ethics Committee immediately you become aware of any information which could cast doubt upon the conduct, safety or an unintended outcome of the study for which approval was given.

If there are amendments which, in your opinion or opinion of your colleagues, could alter radically the nature of the study for which approval was originally given, a revised protocol should be submitted to the Committee.

You will no doubt realise that whilst the Committee has given approval for the study on ethical grounds, it is still necessary for you to obtain approval from the relevant Clinical Directors and /or Chief Executive of the Trust in which the work will be done.

Members of the Committee would like to know the outcome of the study and therefore ask that a report or copy of results is sent to the Secretary in due course.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'T.G. Williams', with a horizontal line extending to the right.

**T.G. WILLIAMS  
CHAIRMAN  
TUNBRIDGE WELLS LOCAL RESEARCH ETHICS COMMITTEE**

## ST THOMAS' HOSPITAL RESEARCH ETHICS COMMITTEE

Medical Committee Office  
Block 5, South Wing

Ext 2097  
Fax 0171 922 8163

8 December 1997

Chairman - Dr G du Mont  
Administrator - Ms S Hirsch

Ms .  
Clinical Psychologist in Training  
Imput Pain Management Centre  
Riddle House  
St Thomas' Hospital

Dear .

**EC97/438     Exploring health beliefs amongst young adults with diabetes**

Thank you for submitting the above application. This application has been approved by Chairman's action and this was ratified at the Research Ethics Committee at its meeting on 25 November 1997.

Please note that this project carries a reference number, noted above, which must be quoted in any future correspondence.

The project number and the principal investigator must be clearly stated on the consent form. If approval is given to named investigators only, these names must also be stated on the form.

In the case of research on patients, a copy of the consent form must be placed in the patient's medical records, together with a note of the date of commencement of his/her participation in the research. A label must appear on the outside cover of the records when the patient is participating in the research.

The investigators must adhere to the published Guidelines of the Committee and provide the Chairman with progress reports if requested. The research should start within 12 months of the date of approval.

Yours sincerely



Dr G du Mont  
Chairman,  
Research Ethics Committee



Preston Hall, Aylesford  
Kent ME20 7NJ  
Tel 01622 710161  
Fax 01622 719802  
Minicom 01622 713005

24 September 1997

Ms.  
4, Northfields  
SPELDHURST  
Tunbridge Wells  
Kent, TN3 OPL

Dear

***AN INVESTIGATION TO EXAMINE THE IMPACT THAT ILLNESS REPRESENTATIONS  
HAVE UPON TREATMENT ADHERENCE AMONGST YOUNG ADULTS (17-25 YEARS)  
WITH INSULIN DEPENDENT DIABETES. FURTHERMORE TO EXPLORE HOW  
REPRESENTATIONS OF ILLNESS RELATE TO A PERSON'S SELF IDENTITY.***

***PROTOCOL NO. 46/97 (Please quote in all correspondence)***

Thank you for submitting the amendments requested at the meeting on Tuesday 2nd September 1997 by the Medway Local Research Ethics Committee.

The members of the Committee present agreed that there is no objection on ethical grounds to the proposed study whose title is given at the head of this letter. I am therefore happy to give you our approval on the understanding that you will follow the protocol as agreed.

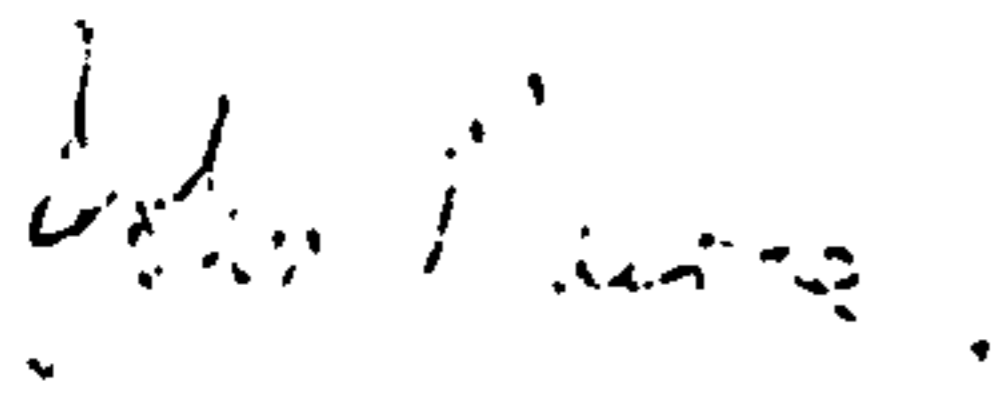
It is your responsibility as the researcher who made the application to notify the Local Research Ethics Committee immediately you become aware of any information which could cast doubt upon the conduct, safety or an unintended outcome of the study for which approval was given.

If there are amendments which, in your opinion or opinion of your colleagues, could alter radically the nature of the study for which approval was originally given, a revised protocol should be submitted to the Committee.

You will no doubt realise that whilst the Committee has given approval for the study on ethical grounds, it is still necessary for you to obtain approval from the Chief Executive/Clinical Director of the Trust in which the work is to be carried out.

Members of the Committee would like to know the outcome of the study and therefore ask that a report or copy of results is sent to the Secretary in due course.

Yours sincerely,

A handwritten signature in cursive script, appearing to read "John Macrae".

**MR. JOHN MACRAE  
CHAIRMAN  
MEDWAY LOCAL RESEARCH ETHICS COMMITTEE**

# MID SUSSEX

NATIONAL HEALTH SERVICE TRUST

The Princess Royal Hospital Haywards Heath West Sussex RH16 4EX TELEPHONE: 01444 441881  
Our Ref: JMB/apn  
Date: 30 September 1997

M/s . Clinical Psychologist in Training  
Salomons Centre  
David Salomons Estate  
Broomhill Road  
Southborough  
Tunbridge Wells Kent TN3 0TG

Dear

**Re: PROJECT ENTITLED: To look at ways young adults understand diabetes, and to explore difficulties some people may have coping with their medical treatments.**

This research project was approved on 29 September 1997 under the standard operating procedure for Chairman's action.

I have to remind you that if this work involves the use of Mid Sussex NHS Trust facilities the approval of the Trust Board must be obtained before this research can begin. The best way to expedite this is to let David Long have a copy of the protocol.

Other NHS Trusts may well have similar requirements and it would be advisable to check if their premises or personnel are involved.

For those projects involving the Mid Sussex NHS Trust there is also a requirement that the prior agreement of support services eg pathology, imaging, pharmacy is obtained before the work begins.

Yours sincerely,

J M Berry  
CHAIRMAN  
EAST UNIT RESEARCH ETHICS COMMITTEE

**Appendix 2**  
**Participants Information Sheet**

**Consent Form For Participation In Research Projects**

**Title of Project:** To look at ways young adults understand diabetes, and to explore difficulties some people may have coping with their medical treatments.

**Principle Investigator:** Psychologist in Clinical Training. Address: Salomons Centre, Broomhill Rd, Southborough, Tunbridge Wells, Kent, TN3 0TG. Tel (01892) 515152.

**Outline Explanation:** I was wondering whether you would be willing to participate in a study exploring how people understand and manage their diabetes? As a clinical psychologist in training I hope to use the study to look at ways of helping people who are finding it hard to cope with having diabetes.

The study has two stages. The first stage would involve ticking boxes on five short questionnaires. This should take no longer than twenty minutes to complete. During the second stage of my study, at a later date, I hope to interview a small number of people in more depth about their views of diabetes. At the end of the questionnaires you can decide whether or not you would be willing to be involved in these interviews if you were selected. As part of the study, if you are agreeable, I will be asking a staff member at the diabetes clinic for your most recent blood test results.

You do not have to participate in any part of this study, and whether you participate or not this study will have no effect upon your treatment. At any time you may withdraw your participation without giving a reason. You may also miss out questions you do not wish to answer.

This research study is separate from the diabetes clinic. The information you give will remain confidential to the researcher and therefore will not be shared with any doctors or nursing staff. Furthermore, all of the information collected during this study will be destroyed when it is no longer needed.

I (name).....

of (address).....

hereby consent to take part in the above investigation, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I understand that I may withdraw from the investigation at any stage without necessarily giving a reason for doing so and this will in no way affect the care I receive as a patient.

Signed (Volunteer)..... Date.....

Witness Signature..... Date.....



## Appendix 3

### Background information Sheet

**BACKGROUND INFORMATION SHEET**

Age.....

Sex: Male..... Female..... please tick as appropriate.

**How would you describe your cultural or ethnic origin?** please tick as appropriate

- |                         |                                   |
|-------------------------|-----------------------------------|
| a) Afro-Caribbean ..... | d) European (including U.K) ..... |
| b) African .....        | e) Other (please specify).....    |
| c) Asian .....          |                                   |

**Education:** If you have any educational qualifications, please tick the highest qualification you have.

- |                            |                                |
|----------------------------|--------------------------------|
| a) None .....              | d) Undergraduate Degree .....  |
| b) GCSE's (O'levels) ..... | e) Post Graduate .....         |
|                            | (Maters, MSc, PhD)             |
| c) A'levels .....          | f) Other (please specify)..... |

**Occupation:** Please specify.....

**Marital Status**

Single ..... Married..... Living with Partner.....

**Hospital Admissions:**

Have you had any hospital admissions in the past twelve months relating to your diabetes.

No..... Yes..... please specify how many admissions.....

**Diabetes History:**

How old were you when you were first diagnosed as having diabetes.....

**Insulin Prescription:** (as recommended by your doctor)

Name of Insulin .....

Dosage (amount per day) .....

Number of injections per day.....

## Appendix 4

### Illness Perception Questionnaire

## What the questionnaire is about

- This questionnaire will help us to find out more about what you think about your illness and treatment.
- There are no right or wrong answers to the questions.
- We are interested in your personal views rather than what your doctor or anyone else might think.

This questionnaire is completely confidential.  
It will be seen only by the researchers and not by any of the staff who are looking after you.

## How to fill it out

- Please answer the questions as completely and honestly as possible.
- Most of the questions can be answered by ticking a box
- Answer each of the questions in turn
- Please don't feel that you have to spend a long time over each question. Often the first answer that comes to you is the best.
- Please answer every question

# YOUR VIEWS ABOUT YOUR DIABETES

Please tick how often you experience the following *symptoms as part of your diabetes*

SYMPTOM	ALL THE TIME	FREQUENTLY	OCCASIONALLY	NEVER
Pain				
Nausea				
Breathlessness				
Weight Loss				
Fatigue				
Stiff Joints				
Sore Eyes				
Headaches				
Upset Stomach				
Sleep Difficulties				
Dizziness				
Loss of Strength				

- We are interested in your own personal views of how you now see your diabetes.
- These are statements other people have made about their diabetes.
- Please indicate how much you agree or disagree with the following statements about your diabetes.

	VIEWS ABOUT YOUR DIABETES	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
IP1	A germ or virus caused my diabetes					
IP2	Diet played a major role in causing my diabetes					
IP3	Pollution of the environment caused my diabetes					
IP4	My diabetes is heredity - it runs in my family					
IP5	It was just by chance that I became ill					
IP6	Stress was a major factor in causing my diabetes					
IP7	My diabetes is largely due to my own behaviour					
IP8	Other people played a large role in causing my diabetes					
IP9	My diabetes was caused by poor medical care in the past					
IP10	My state of mind played a major part in causing my diabetes					

# YOUR VIEWS ABOUT YOUR DIABETES (Continued)

	<b>VIEWS ABOUT YOUR DIABETES</b>	<b>STRONGLY AGREE</b>	<b>AGREE</b>	<b>NEITHER AGREE NOR DISAGREE</b>	<b>DISAGREE</b>	<b>STRONGLY DISAGREE</b>
IP11	My diabetes will last a short time					
IP12	My diabetes is likely to be permanent rather than temporary					
IP13	My diabetes will last for a long time					
IP14	My diabetes is a serious condition					
IP15	My diabetes has had major consequences on my life					
IP16	My diabetes has become easier to live with					
IP17	My diabetes has not had much effect on my life					
IP18	My diabetes has strongly affected the way others see me					
IP19	My diabetes has serious economic and financial consequences					
IP20	My diabetes has strongly affected the way I see myself as a person					
IP21	My diabetes will improve in time with treatment					
IP22	There is a lot which I can do to control my symptoms					
IP23	There is very little that can be done to improve my diabetes					
IP24	My treatment will be effective in curing my diabetes					
diab1	Having diabetes prevents me from getting the best out of myself					
diab2	Having diabetes reduces my career options					
diab3	Having diabetes has a bad effect on my close relationships					
IP25	Recovery from my diabetes is largely dependent on chance or fate					
IP26	What I do can determine whether my diabetes gets better or worse					

Appendix 5

Medication Beliefs Questionnaire

# YOUR VIEWS ABOUT INSULIN PRESCRIBED FOR YOU

*We would like to ask you about your personal views about insulin prescribed for you.  
These are statements other people have made about their insulin.  
Please show how much you agree or disagree with them by ticking the appropriate box.*

**There are no right and wrong answers.  
We are interested in your personal views**

Views about INSULIN PRESCRIBED FOR YOU:	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
My health, at present, depends on my insulin					
Having to take insulin worries me					
My life would be impossible without my insulin					
I sometimes worry about long-term effects of my insulin					
Without my insulin I would be very ill					
My insulin is a mystery to me					
I worry that insulin will affect my weight					
My health in the future will depend on my insulin					
My insulin disrupts my life					
I sometimes worry about becoming too dependent on my insulin					
Insulin does me more harm than good					
My insulin gives me unpleasant side-effects					
I sometimes worry that insulin will cause a 'hypo'					
Having to use insulin interferes with my social life					
I find that injecting insulin is painful					
My insulin protects me from becoming worse					
I have been given enough information about my insulin					
My insulin might become less effective if I use it regularly					



## Appendix 6

### Short Form -36 Health Survey

# THE SHORT FORM 36 HEALTH SURVEY QUESTIONNAIRE (SF-36™)

The following questions ask for your views about your health, how you feel and how well you are able to do your usual activities. If you are unsure about how to answer any questions please give the best answer you can and make any of your own comments if you like. Do not spend too much time in answering as your immediate response is likely to be the most accurate.

1. In general, would you say your health is:

*(Please tick one box)*

Excellent

Very good

Good

Fair

Poor

2. Compared to one year ago, how would you rate your health in general now?

*(Please tick one box)*

Much better than one year ago

Somewhat better than one year ago

About the same

Somewhat worse now than one year ago

Much worse now than one year ago

3. **HEALTH AND DAILY ACTIVITIES**

The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much?

*(Please tick one box on each line)*

		Yes, limited a lot	Yes, limited a little	No, not limited at all
a)	<b>Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	<b>Moderate activities, such as moving a table, pushing a vacuum, bowling or playing golf</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	Lifting or carrying groceries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	Climbing several flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Climbing one flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f)	Bending, kneeling or stooping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g)	Walking more than a mile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h)	Walking half a mile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i)	Walking 100 yards	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j)	Bathing and dressing yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

*(Please answer Yes or No to each question)*

		Yes	No
a)	Cut down on the amount of time you spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>
b)	Accomplished less than you would like	<input type="checkbox"/>	<input type="checkbox"/>
c)	Were limited in the kind of work or other activities	<input type="checkbox"/>	<input type="checkbox"/>
d)	Had difficulty performing the work or other activities (eg it took more effort)	<input type="checkbox"/>	<input type="checkbox"/>

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

*(Please answer Yes or No to each question)*

- |   | Yes                      | No                       |
|---|--------------------------|--------------------------|
| a) Cut down on the amount of time you spent on work or other activities | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Accomplished less than you would like                                | <input type="checkbox"/> | <input type="checkbox"/> |
| c) Didn't do work or other activities as carefully as usual             | <input type="checkbox"/> | <input type="checkbox"/> |

6. During the past 4 weeks, to what extent have your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

*(Please tick one box)*

Not at all

Slightly

Moderately

Quite a bit

Extremely

7. How much bodily pain have you had during the past 4 weeks?

*(Please tick one box)*

None

Very mild

Mild

Moderate

Severe

Very Severe

8. During the past 4 weeks how much did pain interfere with your normal work (including work both outside the home and housework)?

*(Please tick one box)*

Not at all

A little bit

Moderately

Quite a bit

Extremely

**YOUR FEELINGS**

9. These questions are about how you feel and how things have been with you during the past month. (For each question, please indicate the one answer that comes closest to the way you have been feeling).

*(Please tick one box on each line)*

	How much time during the last month:	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a)	Did you feel full of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	Have you been a very nervous person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	Have you felt so down in the dumps that nothing could cheer you up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e)	Did you have a lot of energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f)	Have you felt downhearted and low?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g)	Did you feel worn out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h)	Have you been a happy person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i)	Did you feel tired?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j)	Has your health limited your social activities (like visiting friends or close relatives)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**HEALTH IN GENERAL**

10. Please choose the answer that best describes how true or false each of the following statements is for you.

*(Please tick one box on each line)*

		Definitely true	Mostly true	Not sure	Mostly false	Definitely false
a)	I seem to get ill more easily than other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	I am as healthy as anybody I know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	I expect my health to get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	My health is excellent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix 7

### Summary of Diabetes Self Care Activities Questionnaire

## SUMMARY OF DIABETES SELF-CARE ACTIVITIES

**Instructions :** Thank you for taking the time to fill this out. The questions below ask you about your diabetes self-care activities *during the past 7 days*. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick. Please answers the questions as honestly and accurately as you can. Your responses will be confidential.

### DIET

The first few questions ask about your eating habits over the last 7 days. If you have not been given a specific diet by your doctor or dietician, answer Question 1 according to the general guidelines you have received.

1. How often did you follow your recommended diet over last 7 days?

Always \_\_\_\_\_ Usually \_\_\_\_\_ Sometimes \_\_\_\_\_ Rarely \_\_\_\_\_ Never \_\_\_\_\_

2. What percentage of the time did you successfully limit your calories as recommended in healthy eating for diabetes control?

(0%) \_\_\_\_\_ (25%) \_\_\_\_\_ (50%) \_\_\_\_\_ (75%) \_\_\_\_\_ (100%) \_\_\_\_\_  
None of the time      Some of the time      About half of the time      Most of the time      All of the time

3. During the past week, what percentage of your meals included high fibre foods, such as fresh fruits, fresh vegetables, whole grain breads, dried beans, peas, or bran?

(0%) \_\_\_\_\_ 25%) \_\_\_\_\_ (50%) \_\_\_\_\_ (75%) \_\_\_\_\_ (100%) \_\_\_\_\_  
None of my meals      Some of my meals      About haif of my meals      Most of my meals      All of my meals

4. During the past week, what percentage of your meals included high fat foods such as butter, ice cream, oil, nuts and seeds, mayonnaise, avocado, deep-fried food, salad dressing, bacon, other meat with fat or skin?

(0%) \_\_\_\_\_ (25%) \_\_\_\_\_ (50%) \_\_\_\_\_ (75%) \_\_\_\_\_ (100%) \_\_\_\_\_

None of my meals      Some of my meals      About half of my meals      Most of my meals      All of my meals

5. During the past week what percentage (how many) of your meals included sweets and desserts such as pie, cake, jelly, soft drinks (regular, not diet drinks), or cookies?

0% \_\_\_\_\_ 25% \_\_\_\_\_ 50% \_\_\_\_\_ 75% \_\_\_\_\_ 100% \_\_\_\_\_

None of my meals      Some of my meals      About half of my meals      Most of my meals      All of my meals

### EXERCISE

6. On how many of the last 7 days did you participate in at least 20 minutes of physical exercise?

0      1      2      3      4      5      6      7

7. What percentage of the time did you exercise the amount suggested by your doctor or diabetes nurse? ( For example, if your doctor recommended 30 minutes of activity.)

0% \_\_\_\_\_ 25% \_\_\_\_\_ 50% \_\_\_\_\_ 75% \_\_\_\_\_ 100% \_\_\_\_\_ ?? \_\_\_\_\_

None      Some      About half the amount advised      Most      All      No advice given

8. On how many of the last days did you participate in a specific exercise session other than what you do around the house or as part of your work?

0      1      2      3      4      5      6      7



## GLUCOSE TESTING

9. On how many of the last 7 days (that you were not sick) did you test your glucose (blood sugar) level?

Every day \_\_\_\_\_ Most days \_\_\_\_\_ Some days \_\_\_\_\_ None of those days \_\_\_\_\_

10. Over the last 7 days (that you were not sick) what percentage of the glucose (blood sugar or urine) tests recommended by your doctor did you actually perform?

0% \_\_\_\_\_ 25% \_\_\_\_\_ 50% \_\_\_\_\_ 75% \_\_\_\_\_ 100% \_\_\_\_\_  
None of them    Some of them    About half of them    Most of them    All of them

## DIABETES MEDICATION

11. How many of your recommended insulin injections did you take in the last 7 days as advised by your doctor? (remember there are no right or wrong answers, we are interested in the way you manage your diabetes).

0% \_\_\_\_\_ 25% \_\_\_\_\_ 50% \_\_\_\_\_ 75% \_\_\_\_\_ 100% \_\_\_\_\_  
None of them    Some of them    About half of them    Most of them    All of them

## Appendix 8

### Insulin Adherence Measure

## QUESTIONS ABOUT USING YOUR INSULIN

- Many people find a way of using their insulin which suits them.
- This may differ from the instructions on the label or from what their doctor has said.
- We would like to ask you a few questions about how you use your insulin

Here are some ways in which people have said that they use their insulin

For each of the statements, please tick the box which best applies to you

		ALWAYS	OFTEN	SOMETIMES	RARELY	NEVER
ad1	I use my insulin regularly every day					
ad2	I avoid using my insulin if I can					
ad3	I forget to take my insulin					
ad4	I stop taking my insulin for a while					
ad5	I take my insulin exactly as advised by the doctor					
ad6	I decide to miss out a dose					
wt1	I alter my insulin to help control my weight					
ad7	Instead of exactly following the doctors advice, I use my insulin only when I really need to					

**THANK YOU VERY MUCH FOR COMPLETING THE QUESTIONNAIRE**

**1) Would you be willing to be contacted by the researcher if you were chosen for a follow-up interview.**

No.....

Yes.... Do you have a contact telephone number and when would be the most convenient time of day to ring.

Or

Would you prefer to be contacted by letter. Please give details of your contact address

**2) Would you like a report on the research once it is completed in Aug 1998.**

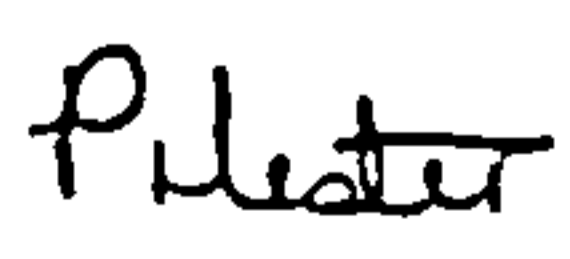
Yes.... Please leave a postal address, if you haven't already given one above.

No.....

**Please put the questionnaire in the envelope provided and seal it. The postage is free.**

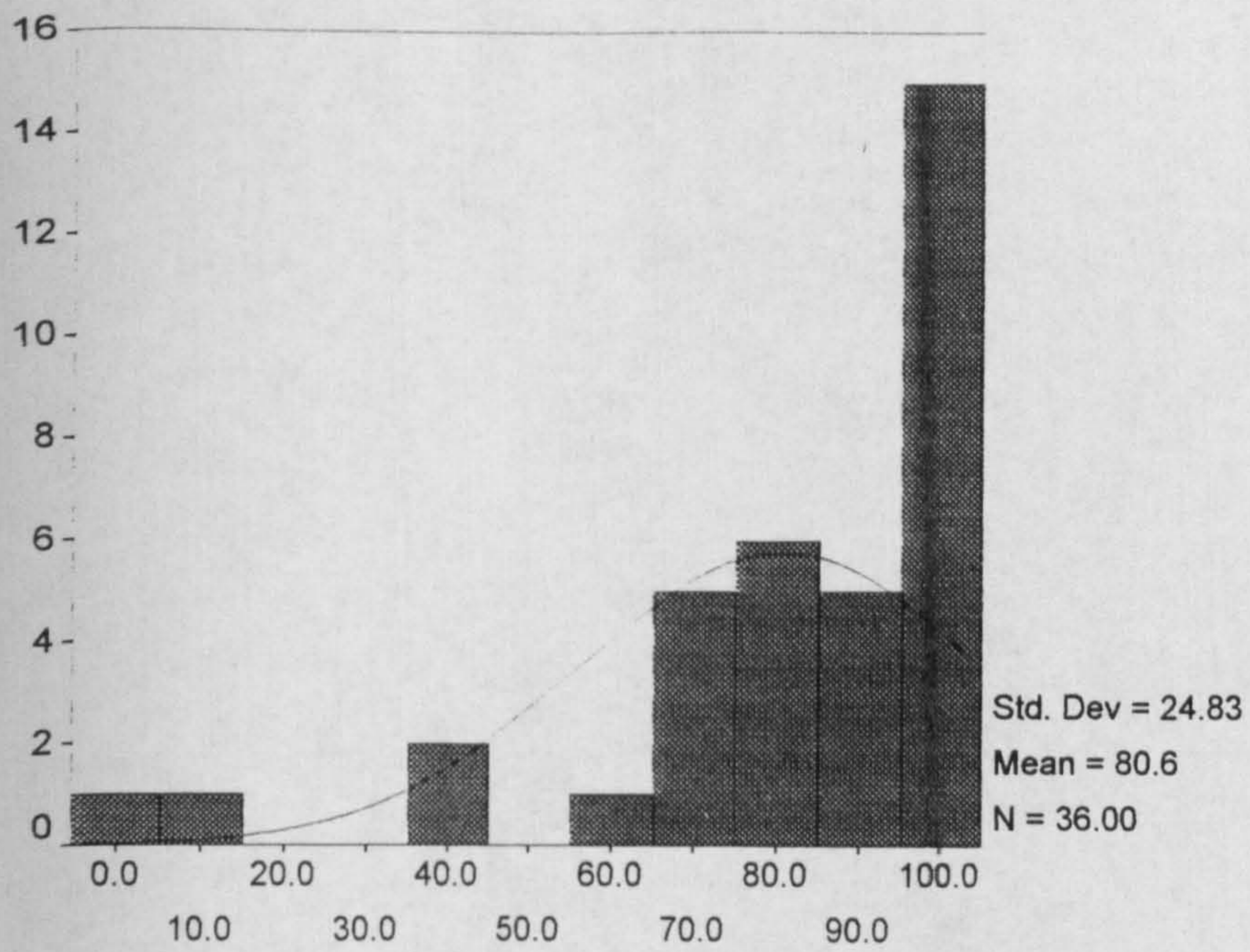
**If you are filling in the questionnaire whilst at the diabetes clinic please place it in the postal tray on the diabetes clinics receptionists desk. The questionnaire will be posted directly to me and as soon as I receive it the two sheets (i.e consent form and this sheet) with your name and address on will be removed and kept separately, to ensure total confidentiality.**

Many Thanks

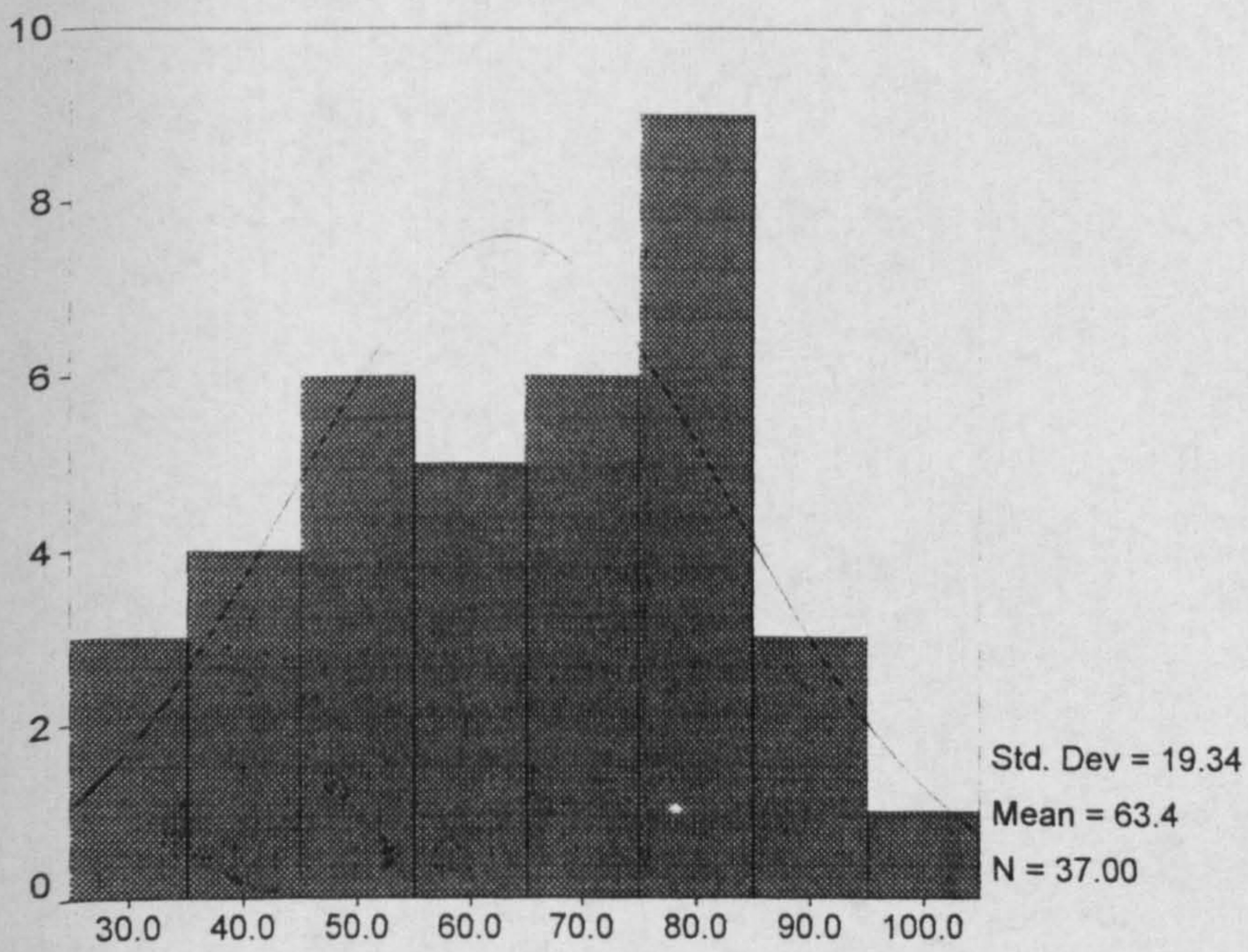
  
Pippa Hester

## Appendix 9

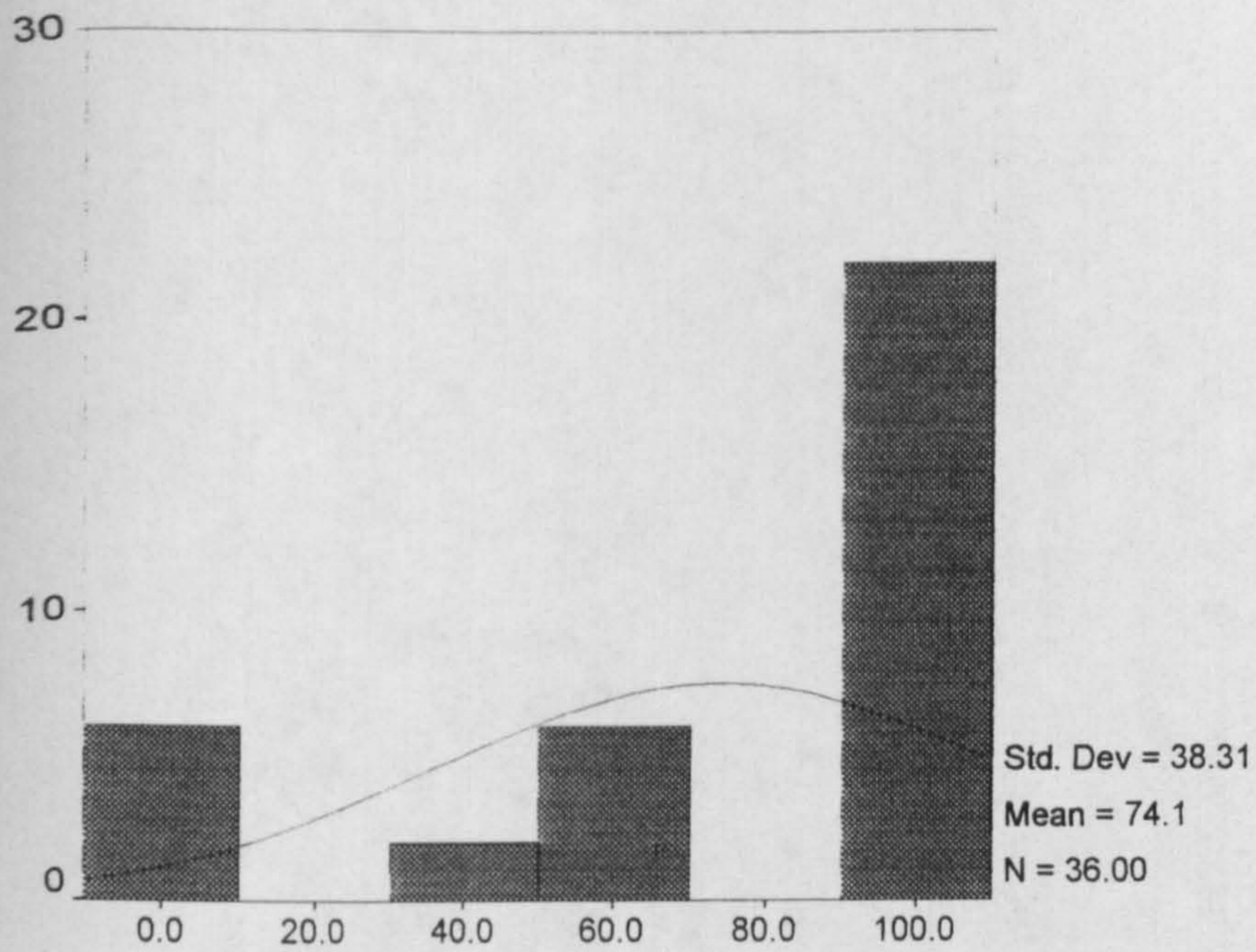
Examples of Histograms which typically reflect the distribution of scores. The histograms shown were derived from a selection of quality of life measures within the age group 17- 21 years.



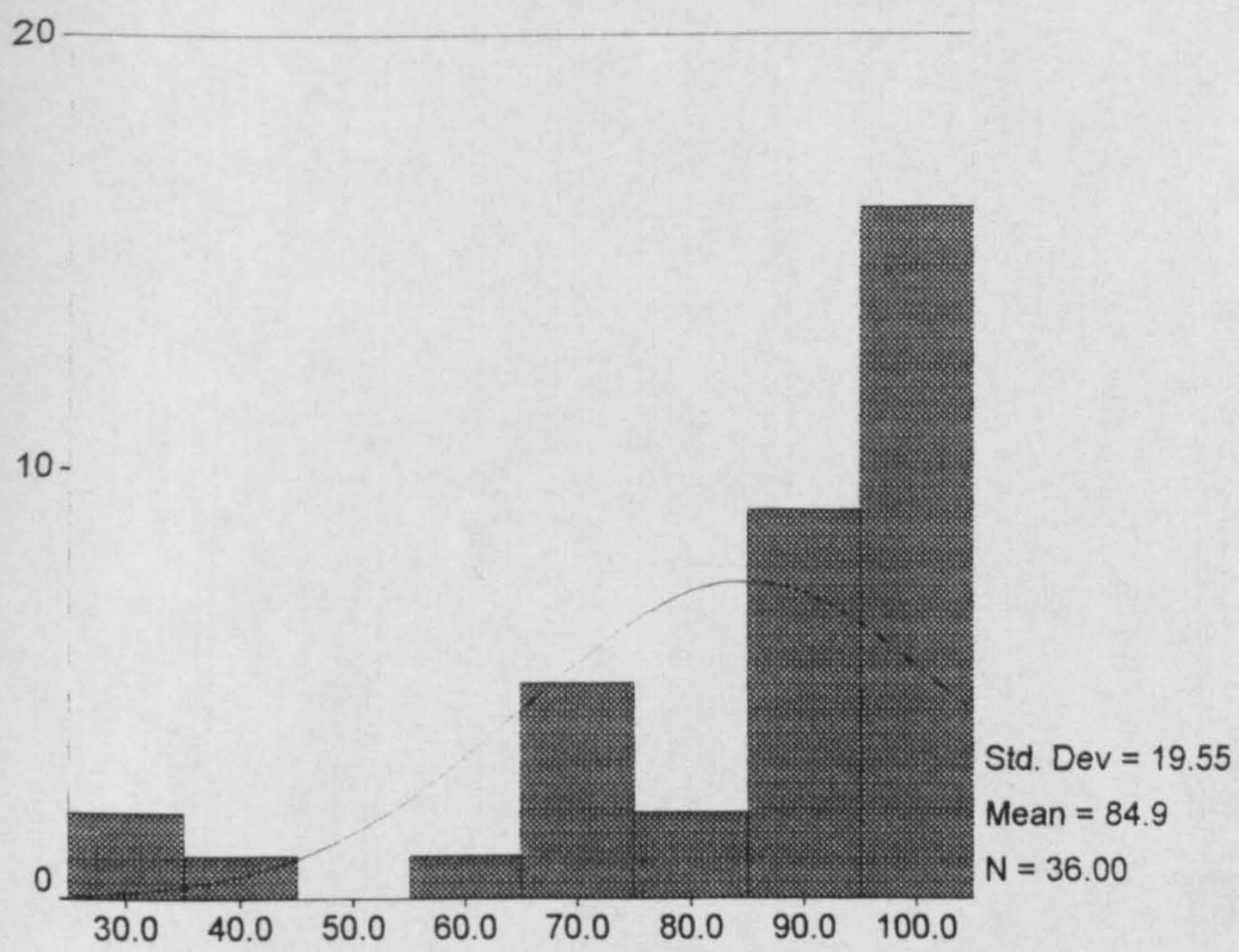
pain



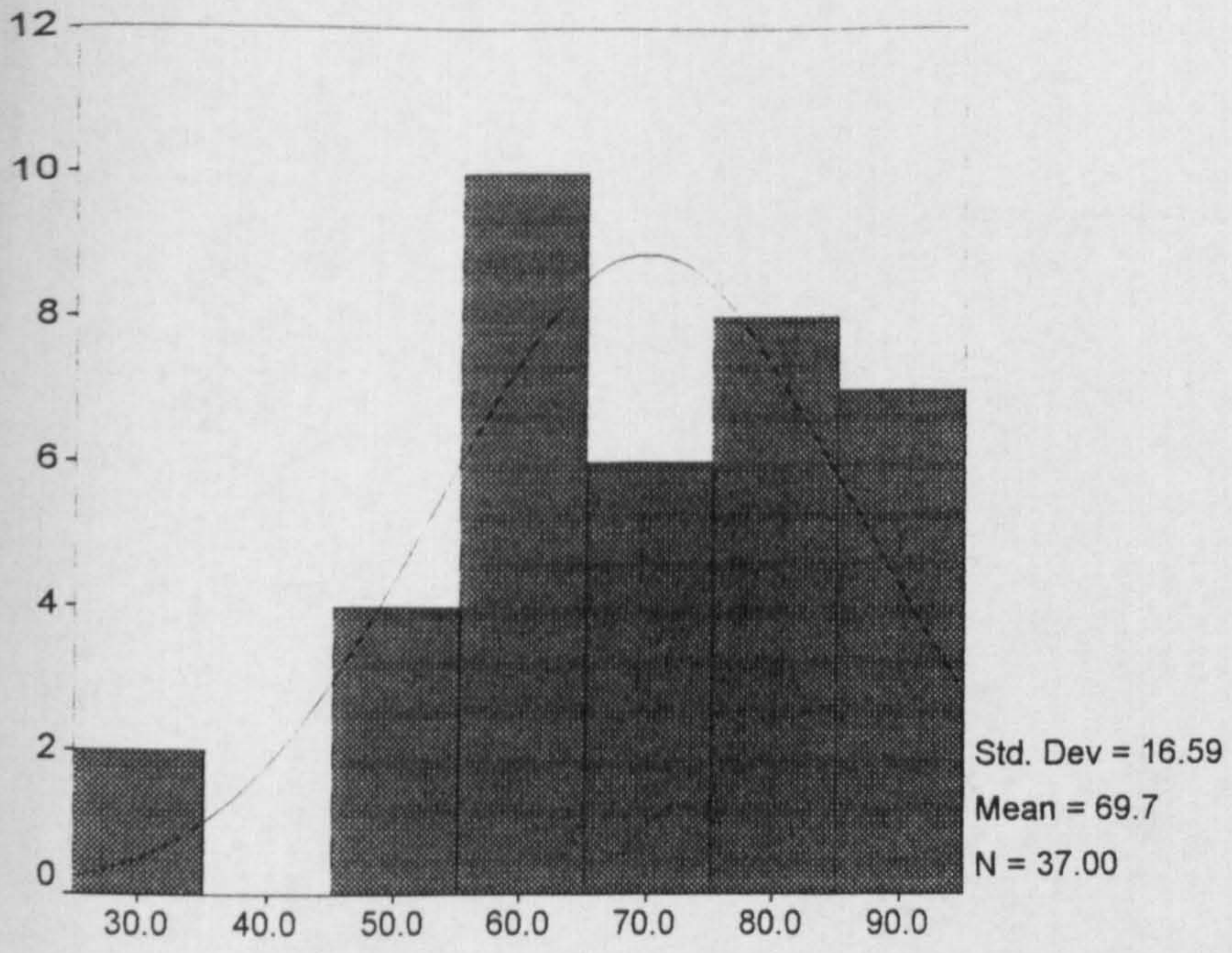
general health perception



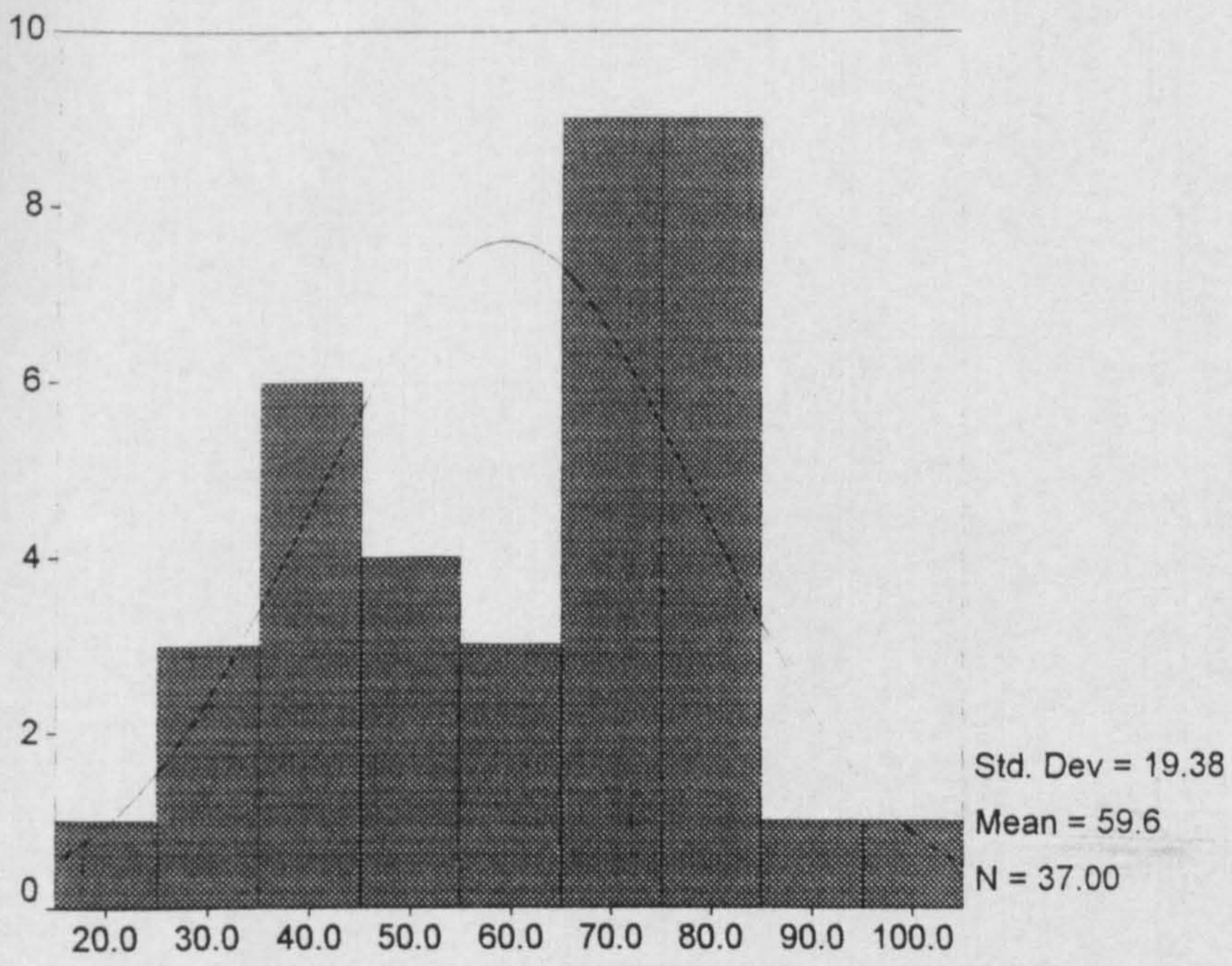
role limitation due to emotional problems



social functioning

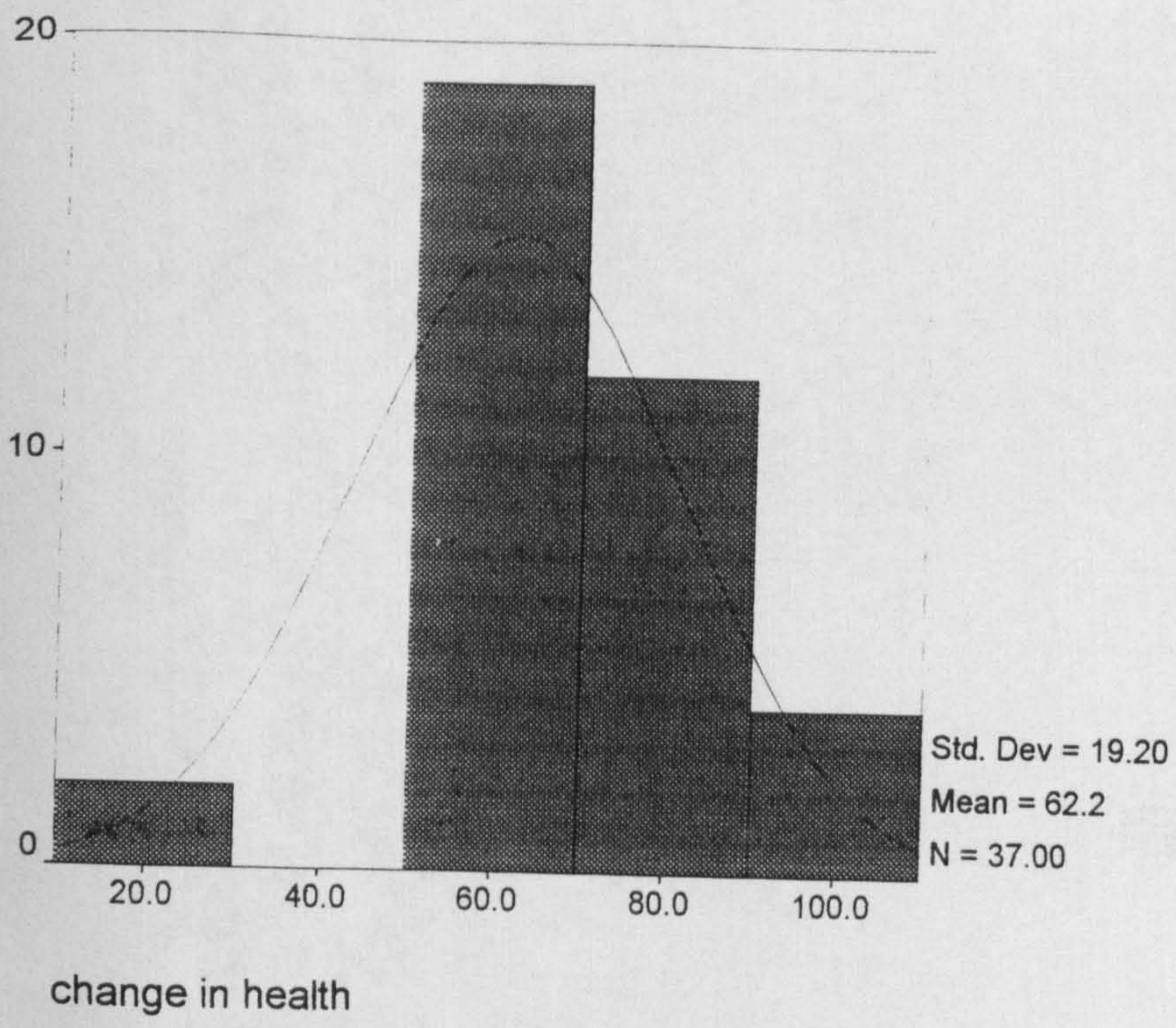


mental health



GHQEV (Energy & Vitality)







*Library authorisation form  
DClinPsychol*

Please return this form to the Assistant Director (Registration and Conferments), Open University Validation Services, 344-354 Gray's Inn Road, London WC1X 8BP.

Student: PHILIPPA HESTER-SMITH

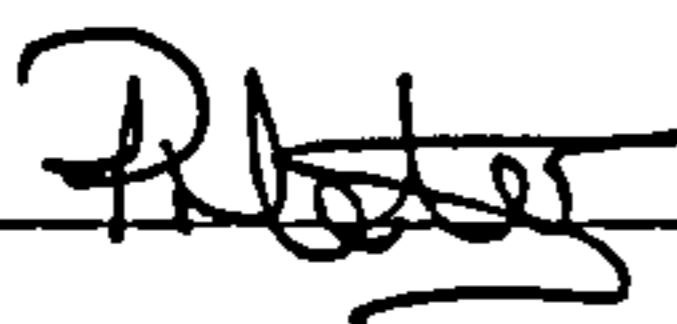
Validated institution: \_\_\_\_\_

Degree for which the thesis is submitted: Doctor of Clinical Psychology

Thesis title: Treatment A An investigation to examine the relationship between illness Representations, quality of life, & treatment adherence amongst young adults with insulin dependent diabetes

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I confirm that I am willing for my thesis to be made available to readers by the Open University Library and for it to be photocopied, subject to the discretion of the Librarian.

Signed:  Date: 4.11.98

**Part 2 British Library Authorisation**

If you want a copy of your thesis to be available on loan to the British Library Thesis Service as and when it is requested, you must sign a British Library Doctoral Thesis Agreement Form and return it to the Research Degrees Office of the University together with this form. The British Library will publicize the details of your thesis and may request a copy on loan from the University Library. Information on the presentation of the thesis is given in the Agreement form.

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