

# The Development of a Scale to Assess Attitudes to Advance Statements

Thesis Submitted to The University of Leicester,  
School of Psychology – Clinical Section, Faculty of Medicine,  
in partial fulfilment of the degree of Doctorate in Clinical Psychology

By

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July 2007

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## Statement of Originality

The accompanying Thesis submitted for the degree of Doctorate in Clinical Psychology entitled 'The Development of a Scale to Assess Attitudes to Advance Statements' is based on the work conducted by the author in the Department of Clinical Psychology at the University of Leicester mainly during the period between July 2006 and July 2007.

All the work recorded in this Thesis is original unless otherwise acknowledged in the text or by references.

None of this work has been submitted for another degree in this or any other University.

## Acknowledgements

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	Excluding References	Including References
Part One: Literature Review	7923	9183
Part Two: Research Report	11995	13324
Part Three: Critical Appraisal	3907	3989
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# The Development of a Scale to Assess Attitudes to Advance Statements

Daniella Wickett, Trainee Clinical Psychologist

## Thesis Abstract

### Part One: Literature Review

*Purpose:* To systematically review the evidence for the psychological benefits to patients of perceived control over health and health care.

*Method:* A systematic electronic search was conducted using a combination of search terms. A total of 32 articles were selected for review.

*Results:* Studies appeared to suggest that a general sense of perceived control was related to favourable outcome. Control over symptoms, illness and treatment might all have beneficial effects for psychological adjustment and well being. The evidence is less consistent for general and specific health locus of control beliefs, although there is some evidence to suggest mediational and moderational roles.

*Conclusions:* Perceived control is an important variable for understanding the relationship between physical illness and adjustment or distress.

### Part Two: Research Report

*Aim:* The current study aimed to develop an acceptable, valid and reliable scale that could be used to assess attitudes to Advance Statements with people aged over 50 years old.

*Method:* Scale items were developed from a qualitative analysis of the literature. An initial scale of 40-items was piloted with 46 participants. Following feedback from the pilot sample and a focus group, the scale was amended. The responses from 180 participants were used to analyse the internal consistency of the scale. Principal components analysis (using varimax rotation) was used to determine the component structure and identify items for removal.

*Results:* A two-factor 28-item scale was produced, which had a coefficient alpha of 0.862 and split-half reliability of 0.890, suggesting the scale to be reliable.

*Discussion:* The scale has a number of potential clinical and research applications. However, further work is needed to establish psychometric properties and generalisability.

### Part Three: Critical Appraisal

A personal reflection on the research process is provided, considering the various stages of the research process and a summary of reflections.

## **Part One: Literature Review**

**What is the Evidence that Patients' Perceiving Control Over  
Their Health and Healthcare is of Psychological Benefit?**

## 1. Abstract

*Purpose:* To systematically review the evidence for the psychological benefits to patients of perceived control over health and health care.

*Method:* A systematic electronic search of PsycINFO, PsycARTICLE, SCOPUS and Web of Science databases was conducted using a combination of search terms. A total of 32 articles were selected for review based on specified inclusion criteria.

*Results:* The review highlighted varied findings for the relationship between perceived personal control and psychological outcomes. Studies appeared to suggest that a general sense of perceived control was related to favourable outcome. Additionally, control over symptoms, illness and treatment might all have beneficial effects for psychological adjustment and well-being. The evidence is less consistent for health locus of control and illness-specific locus of control beliefs, although there is some evidence to suggest that control has mediational and moderational roles with other variables.

*Conclusions:* Perceived control is an important variable for understanding the relationship between physical illness and adjustment or distress. However, the relationship between perceived control and psychological outcomes is often complex.

## 2. Introduction

The concept of control has been of interest to theorists and researchers for over 40 years. It has attracted a great deal of clinical and research interest from those seeking to understand the factors that differentially effect the adjustment, well-being and behaviour of different people in the face of similar circumstances. The role of control in relation to physical health problems has been of particular interest and a vast body of ever-growing research in this area has developed.

### 2.1 Definitions of Control

According to Wallhagen and Brod (1997), the majority of the literature has defined control in relation to amount of personal influence that individuals believe they have over desired outcomes. However, it has been noted that control has been conceptualised and defined in a variety of ways, and that there is a lack of clarity about what constitutes control (Wallhagen, 1998). The construct has been inappropriately equated with concepts such as choice, power, predictability and responsibility; is theoretically overlapped with other concepts, such as coping; and has been viewed as both an action and an outcome (Wallhagen, 1998). It has been suggested that some of the contradictory findings in the research literature may have arisen due to the ways in which control has been conceptualised, operationalised and assessed (Wallhagen, 1998). For the purposes of this review, 'control' is broadly defined as the perception of one's abilities to obtain positively valued outcomes and avoid negative outcomes (Devins, Binik, Hutchinson, Hollomby, Barre and Guttman, 1983-4), and is considered as a independent variable which may predict outcome in terms of psychological well-being.

## 2.2 Theories of Control

There are a variety of theoretical models that seek to provide an explanation for the role and relative importance of control in relation to behaviour or outcome. These theories include: internal-external locus of control (Rotter, 1966); the self-regulatory model of illness (Leventhal, Meyer, & Nerenz, 1980); the conceptual model of coping with serious illness (Stewart, 1983); and control appraisal theory (Folkman, 1984).

Locus of control theory (Rotter, 1966) proposes that the expectation that behaviour will result in a given reinforcement can be perceived by an individual as contingent on one's own action or upon external factors such as chance (Wallhagen, 1998). The self-regulatory model of illness (Leventhal, Meyer, & Nerenz, 1980) suggests that individuals develop cognitive representations of illness in the face of health threat, which direct their emotional and behavioural responses (Michie, 2005). These representations include: identity (the label given to the illness and symptoms); beliefs about consequences; cause; duration; and controllability or curability of their condition (Michie, 2005). The conceptual model of coping with serious illness (Stewart, 1983), considers personal control as a psychosocial resource that may facilitate coping and adaptation to illness, and may be predictive of psychological and functional recovery outcomes. Within control appraisal theory (Folkman, 1984), locus of control (Rotter, 1966) is viewed as a dispositional control belief and self-efficacy (confidence in ability to behave in ways that will lead to desired outcomes) (Bandura, 1977), as dependent on situation specific factors (Shelley & Pakenham, 2007). Folkman (1984) suggested that in unpredictable situations, locus of control beliefs would be drawn upon, where as in familiar or unambiguous situations, self-efficacy beliefs would supersede locus of control beliefs (Shelley & Pakenham, 2007).

### 2.3 Measurement of Control

Numerous scales have been developed to measure one or more dimensions or aspects of control. Perhaps the most commonly used scale to assess control in relation to health, is the Multidimensional Health Locus of Control Scale (MHLC; Wallston, Wallston & DeVellis, 1978) which conceptualises control as Internal, Powerful Others and Chance. A revised version (Form C) of the MHLC, split the dimension of Powerful Others into 'Doctors' and 'Other People'. This scale has also been adapted for use in numerous studies to focus on illness-specific rather than general health control beliefs, in response to research findings that supports the use of very specific distinctions regarding the aspects of control being assessed (Reed, Taylor & Kemeny, 1993). Numerous researchers have opted to use idiosyncratic and single item measures, in order to assess control with increased specificity. Control has also been assessed by scales within broader measures such as the Control subscale of the Coping with Serious Illness Battery (Stewart, 1983).

A review of the literature considering the evidence for the psychological benefits for patients of perceiving control over their health and health care seems to be required. There is an ever increasing drive in the NHS, towards patient involvement in their health care and in care and treatment decision making. Determining the aspects of control that might be beneficial, for whom, and at what point in a patient's care would be extremely useful for clinicians working with patients with acute, chronic or life-threatening health problems.

It would be impossible within the scope of the present review to consider all of the literature that is available on the construct of control, and this review therefore focuses exclusively on the psychological benefits of perceived control for patients with physical health problems. It is acknowledged that in adopting such a specific focus (and using

specific search terms in combination) that some relevant literature may have been unintentionally excluded. The evidence is reviewed in relation to conceptualisations of control to facilitate an understanding of the role that control might play as a general determinant of the emotional impact of illness (Devins et al, 1983-4). A summary of the studies reviewed including control and outcome variables and measures is presented in Table 1.

### 3. Search Strategy

Articles for this review were obtained in June 2007 using an electronic search of PsycINFO and PsycARTICLES (through EBSCO HOST), and from SCOPUS and Web of Science databases. A total of 32 articles were selected for review. Search terms, search limiters and the selection criteria for the articles reviewed are detailed in Appendix 1.



Authors	Sample	Primary Predictor Variables	Secondary Predictor Variables	Control Measures	Psychological Outcome Variables	Outcome Measures
Affleck et al (1987)	Rheumatology patients (n=92, 66% female)	Personal control over: daily symptoms, future course of illness and care treatment. Healthcare provider control over: daily symptoms and future course of illness	Predictability appraisals. symptom/disease severity	Single item to assess each aspect of control	Mood and psychosocial adjustment	POMS-B, GAIS
Andrykowski & Brady (1994)	Bone marrow transplant (leukaemia) patients (n=69, 45% female)	Health locus of control		MHLC	Psychological distress	POMS, PAIS
Arnold et al (2006)	Chronic obstructive pulmonary disease patients (n=39, 41% female)	Perceived control (over life in general), self-efficacy (control symptoms and maintain function)		Mastery Scale of Perlin & Schooler, Self-Efficacy Scale of Sullivan et al	Quality of Life (physical, psychological and social functioning).	3 subscales of Rand 36-item Health Survey, Cantril's Ladder
Barez et al (2007)	Breast cancer patients (stage I or II) (n=101)	Perceived control, self-efficacy, active coping strategies		Spanish versions of: MAC Scale (excluding avoidance subscale), a researcher created self-efficacy scale and PCS	Loss of adaptation	Spanish versions of: HADS, POMS (shortened version), EORTC (quality of life measure)
Bohachick et al (2002)	Heart transplant patients (n=30, 20% female)	Personal control (general)		Sense of Control Scale from CSIB	Psychosocial resources	CSIB (Social Network Scale, Attachment/Expressive Scale, Understanding Scale, Advice Scale, Information seeking Scale).
Bremer (1995)	End Stage Renal Disease patients (n=138, 49% female)	MHLC (internal, powerful others, chance). For follow up: MHLC (internal, doctors, other people, chance)		MHLC Form B and MHLC Form C for follow up	Emotional rehabilitation and evaluative aspects of life	ABS, IWB.
Bremer et al (1995)	End Stage Renal Disease patients (n=65, 45% female)	Control over life dimensions, Health locus of control (internal, chance, doctors, other people) focused on kidney disease	Illness intrusiveness	Ratings on 11 life dimensions for control and for illness intrusiveness, MHLC- Form C	Mood (positive and negative)	ABS, IWB.

Authors	Sample	Primary Predictor Variables	Secondary Predictor Variables	Control Measures	Psychological Outcome Variables	Outcome Measures
Carver et al (2000)	Early stage breast cancer (study 1, n=147 and study 2, n=202)	Control over recurrence (personal or external). Expectancies of recurrence		Single item (dichotomous response option)	Study 1: Distress Study 2: Emotional adjustment	Study 1: POMS (for 69 of the sample), and ABS negative scales (for 78 of the sample) Study 2: POMS, CES-D, 11 items of Andrew & Withey (1976) Quality of Life
Chaney et al (1996)	Rheumatoid arthritis patients (n=58, 81% female)	Attributional style (internal, stable, global)	Perceived illness control	Attributional Style Questionnaire (negative events), single item to rate control over daily symptoms	Depression, helplessness	IDD, Arthritis Helplessness Index
Coulton et al (1989)	Post-hospital care patients (n=264, 70% female)	Decisional control	LOC	2 items to assess who made decision and degree of patient choice, modified LOC (15 item)	Anxiety regarding decision making, adjustment	7 Items to assess decision making anxiety, BSI and 4 items to rate satisfaction
Devins et al (1983-4)	End Stage Renal Disease patients (n=70, 41% female)	Perceived control over life dimensions and 'the illness and its treatment'. Illness intrusiveness		Ratings for control and illness intrusiveness on 11 life dimensions. Ratings for control on 'the illness and its treatment' and 'over dialysis itself' (for some patients)	Negative mood and positive mood	Short form BDI, Rosenberg SES, POMS (depression and vigour subscales), Atkinson 11-point rating of life happiness, checklist of somatic symptoms. Staff completed Hamilton Psychiatric Rating Scale for Depression
Ell & Haywood (1984)	Myocardial Infarction patients (n=75, 40% female)	Social Support	Illness severity Pre-illness stressful life events Sense of control (general)	Sense of Control Scale from CSIB	Psychosocial recovery	CSIB
Evans et al (2000)	HIV infected gay men (n=173)	HLOC (internal, powerful others, chance)	Severity of illness, HIV symptomology	HLOC scale	Distress	BDI, BHS, GARS
Fowers (1994)	Cardiac rehabilitation patients (n=71, 25% female)	Personal control and control by others over health outcomes, personal control over cardiac illness, outcome expectancies	Chronicity, perceived severity and general life stress	MHLC (internal, powerful others, chance), COCRS	Psychological Distress	PAIS – Psychological distress Scale

Authors	Sample	Primary Predictor Variables	Secondary Predictor Variables	Control Measures	Psychological Outcome Variables	Outcome Measures
Friedman et al (1988)	Breast cancer patients (post surgery) (n=67)	Coping style, expression of anger, locus of control over health matters	Stage or severity of illness, duration of illness	HLOC (internal, external)	Psychosocial adjustment, hostility, coping, fighting spirit	PAIS, Buss-Durke Hostility Scale, Moos Coping Scale, cancer specific coping survey, Oral Optimism Questionnaire, Hassles Scale
Griffin & Rabkin (1998)	Advanced AIDS patients (n=42, 19% female)	Perceived control over illness and perceived control over most important consequences of illness, realistic acceptance of illness progression and death		Single items to assess control over illness, most important consequences, and control over consequences	Psychological adjustment	HAM-D, BDI, BHS, DAQ
Helgeson (1992)	Cardiac patients (first event) (n=92, at follow up n=80, 20% female)	Personal control over heart problem and others control over heart problem, HLOC		2 single items to assess personal control and others (vicarious) control, HLOC	Psychological and psychosocial adjustment	Multiple Affect Adjective Checklist (anxiety, depression and hostility subscales), PAIS
Jenkins & Pargament (1988)	Cancer patients (n=62, 65% female)	Perceived Life threat of illness, perceived control over cancer currently (self, other people, god, chance, natural causes), perceived control over emotional reactions		Ratings for degree of control by self, other people, god, chance, natural causes over cancer currently, 3 items from PIER Scale	Psychological adjustment	Rosenberg SES, Life Threat Reactivity Scale of the Millon Behavioural Health Inventory, nurses ratings using BUMP and GAIS
Lowery et al (1993)	Breast cancer patients (n=195)	Causal thinking, perceived control		Single questions to assess personal control over the course of cancer and cause of cancer, others control over the course of cancer and cause of cancer, loss of control over things since diagnosis, MHLC – Form A (internal, external, chance)	Psychological adjustment	PAIS, Impact of Events Scale, interviewer completed GAIS
Marks et al (1986)	Newly diagnosed cancer patients (n=137, 34% female)	MHLC (self, doctor, chance), expectations of treatment efficacy		9 items from MHLC – 3 from each subscale, 3 items from Rotter I-E LOC scale	Short term psychological adjustment	Zung Depression Scale – psychological functioning items, one item to assess sadness
Michie et al (2005)	Cardiac rehabilitation patients (n=62, at 8 month follow-up n=29)	Cognitive representations of illness (incl. cure/control) and self-efficacy		Illness Perceptions Questionnaire, single items to assess confidence in ability to change behaviour	Mood and quality of life	HADS, SF-12 (short form health survey)

Authors	Sample	Primary Predictor Variables	Secondary Predictor Variables	Control Measures	Psychological Outcome Variables	Outcome Measures
Norton et al (2005)	Ovarian cancer patients (n=143)	Physical impairment, perceived unsupportive behaviours	Perceived control over course of illness and treatment, perceived control over emotional responses to illness. Self Esteem	3 items to assess perceived control over course of illness and treatment, 2 items to assess control over emotional responses to illness	Psychological distress	12 item Psychological Distress Scale of Mental Health Inventory-18
Reed et al (1993)	Gay or bisexual men with AIDS (n=24)	Control beliefs, personal and vicarious control over symptoms, control over illness, control over medical care or treatment		Rotter LOC Scale (16 item), individual items to assess personal and vicarious control over symptoms, control over illness, control over medical care or treatment	Global adjustment	Ratings of satisfaction with life across various domains, rating of satisfaction with life, IWB, ABS, The Hopelessness Scale, Rosenberg SES, TMAS – negative affectivity
Schiaffino & Revenson (1992)	Rheumatoid arthritis patients (n=64, 90% female)	Perceived control (outcome expectancies), self-efficacy, causal attributions (internal, stable, global)		2 items from Implicit Models of illness Questionnaire – RA is controllable and RA controllable by oneself, 3 items to assess ability to manage with pain, physical limitations and daily activities, attributions for a recent symptom flare on scales of internality, stability and globality	Depression	CES-D
Shelley & Pakenham (2007)	Coronary artery bypass graft patients (n=80, 20% female)	External LOC, self-efficacy in relation to current heart problem		Powerful Others Subscale of MHLC – Form A	Distress (depression, anxiety and stress), pain	DASS – short form, visual analogue scale for pain
Sun & Stewart (2000)	Chinese nasopharyngeal cancer patients (n=152, 31% female)	Social Support MHLC (internal, chance, powerful others) reflecting patients condition		MHLC – Form B (translated and altered to reflect condition)	Psychological well-being, stress, neuroticism	Chinese version of GHQ-30, appraised level of stress in relation to 4 cancer related stressors, Chinese Neuroticism Questionnaire
Talbot et al (1999)	Type 2 diabetes patients (n=237, 45% female)	Diabetes intrusiveness	Personal control	Internal HLOC scale of MHLC (French Canadian version), translated version of Internal subscale of Diabetes LOC Scale	Depressive symptomology	French-Canadian versions of: BDI – short form, HADS – depression scale

Authors	Sample	Primary Predictor Variables	Secondary Predictor Variables	Control Measures	Psychological Outcome Variables	Outcome Measures
Thompson et al (1993)	Cancer patients (n=71, 63% female)	Perceived control over emotions, physical symptoms, relationships, medical care, disease progression and general perception of control		9 items to assess: emotions and physical symptoms (2) , relationships (3), medical care (2), disease progression (1), general control (1)	Psychological maladjustment	CES-D, depression and anxiety subscales of SCL-R-90
Tomich & Helgeson (2006)	Breast cancer patients (n=35) and matched controls (n=35)	Self-esteem, optimism, personal control		Individual items to assess: control over future course of illness, day to day symptoms, emotions and feelings about illness	Physical health and mental health, benefit finding	SF-36 from the Medical Outcomes Study (quality of life measure), Benefit Finding Scale.
Wallhagen & Brod (1997)	Parkinson's Disease patients (n=101, 41% female)	Control over disease progression and daily symptoms		Two single items	Well-being	MOS
Watson et al (1990)	Cancer patients (n=59, more than 75% female)	Cancer HLOC (internal cause, internal course and religious control)		Cancer LOC	Psychological adjustment	HADS, Mental Adjustment to Cancer Scale, Courtauld Emotional Control Scale
White et al (2006)	Chronic Fatigue Syndrome (CFS) patients (n=105, 88% female)	Causal attributions, CFS HLOC (self, powerful others, chance)		Asked for theories about what caused CFS, MHLC (altered to be CFS specific)	Psychological adjustment	BSI – depression and anxiety subscales, 5 item measure of ruminative thoughts

*Table 1: Summary of study populations, and predictor and outcome variables and measures*

#### Abbreviations

ABS	Affect Balance Scale	CSIB	Coping with Serious Illness Battery	HAM-D	Hamilton Depression Rating Scale	PAIS	Psychological Adjustment to Illness Scale
BDI	Beck Depression Scale	DASS	Depression, Anxiety and Distress Scale	IDD	Inventory to Diagnose Depression	PCS	Personal Competence Scale
BHS	Beck Hopelessness Scale	DAQ	Death Anxiety Questionnaire	IWB	Index of Well Being	PIER	Perceived Inevitability of Emotional Reactions
BSI	Brief Symptom Inventory	GAIS	Global Adjustment to Illness Scale	LOC	Locus of Control	POMS	Profile of Mood States
BUMP	Behavioural Upset in Medical Patients	GARS	Global Assessment of Recent Stress	MAC	Mental Adjustment to Cancer	Rosenberg SES	Rosenberg Self-Esteem Scale
CES-D	Center for Epidemiological Studies - Depression	GHQ	General Health Questionnaire	MHLC	Multidimensional Health Locus of Control	SCL-R-90	Symptom Checklist (Revised)
COCRS	Control Over Cardiac Recovery Scale	HADS	Hospital Anxiety and Depression Scale	MOS	Medical Outcomes Study Mental Health Index	TMAS	Taylor Manifest Anxiety Scale

#### 4. Perceived Personal Control

Five studies within the current review examined perceived personal control at a general level, which included some consideration of 'control over health'. The studies considered outcome in terms of anxiety and depression, although many also incorporated additional outcome variables, such as positive affect, physical symptoms or functioning, and social functioning.

Two studies examined the relationship between a general sense of control and psychosocial recovery for patients with heart conditions. Both studies used the Sense of Control Scale from the Coping with Serious Illness Battery (Stewart, 1983) to assess control and the other subscales of the battery to assess outcome. Ell and Haywood (1984) used a sample of patients in recovery following a myocardial infarction. Although, the main focus of their study was examining the role of social support, personal control was found to account for more variance in the majority of outcomes after one year than illness severity or prognosis, pre-illness stressful events and social support (Ell & Haywood, 1984). Bohachick, Taylor, Sereika, Reeder and Anton (2002) examined psychosocial recovery following heart transplantation. Their findings suggested that sense of personal control was relatively stable over time (six months). Patients with a higher sense of control at the time of hospitalisation demonstrated higher levels of optimism, satisfaction with life and well-being, and lower levels of anger and depression at six months post-transplant. The findings further suggested that improvement in psychological outcome was not the result of better functioning, as control and functioning were almost unrelated.

Devins et al (1983-4) examined the relationship between perceived illness intrusiveness, control and mood for patients with End Stage Renal Disease (ESRD). Control was assessed using ratings for 11 life dimensions, plus ratings for the illness and its treatment, and over dialysis. They found that perceived control was significantly, negatively correlated with perceived intrusiveness, and that increased levels of perceived intrusiveness and decreased perceived control both correlated significantly and uniquely with positive and negative mood (Devins et al, 1983-4).

Arnold, Ranchor, Koeter, deJongste, Wempe, ten Hacken et al (2006) examined whether changes in personal control could predict quality of life following a rehabilitation group for patients with Chronic Obstructive Pulmonary Disease (COPD). Control was conceptualised as personal control over life (assessed using the Mastery Scale of Perlin & Schooler, 1978), and as self-efficacy for the ability to control symptoms and maintain function (assessed using the Self-efficacy Scale of Sullivan, LaCroix, Russo and Katon, 1998). Perceptions of personal control at the start of the group were not related to quality of life at the end of the group. However, changes in self-efficacy for the ability to maintain function contributed to significant changes in social and psychological functioning.

Barez, Blasco, Fernandez-Castro & Viladrich (2007) adopted a different approach to the other studies so far reported. In their study, Barez et al (2007) defined perceived control as a latent construct 'made up of self-efficacy, active coping strategies, and a set of beliefs about the capacity of the individual's belief about the control he/she can exert over the situations' (p.23). This construct was considered in relation to outcome in terms of 'loss of adaptation', which was construed as a latent construct comprised of mood state, functional status and physical symptoms. Using structural equation modelling, Barez et al (2007) assessed these constructs with a sample of breast cancer patients at five time points across

the first year after surgery. They suggested that their results demonstrated that ‘perceived control’ and ‘loss of adaptation’ are always highly related, reporting correlations between -0.87 and -0.95 (Barez et al, 2007).

All of these studies suggest that a general sense of control is related to favourable outcomes in terms of adjustment, mood, or social, psychological and/or physical functioning. The positive effect of perceived control was found to be greater than that of social support (Ell & Haywood, 1984), not attributable to improved functioning and sustained at six months (Bohachick et al, 2002). Interestingly, Devins et al (1983-4) found that factors specific to ESRD and its treatment did not make an important contribution to patients’ emotional state, while factors that may apply across a range of medical illnesses (i.e. perceived control and illness intrusiveness) did.

Bohachick et al (2002) suggested that a sense of personal control plays a crucial and direct role for psychological outcomes, and that this may be related to diminished feelings of vulnerability associated with the ‘victimisation experience’ of serious illness (Helgeson, 1992). It is perhaps worth noting that the study by Bohachick et al (1983-4) used a sample of only 30 patients, which may have limited the statistical power. The study by Arnold et al (2006) may have faced similar problems with a sample of 39 patients.

The study by Barez et al (2007), consistently found a very strong negative correlation between perceived control and loss of adaptation. However, it could be argued that the conceptualisation of personal control utilised by Barez et al (2007) is actually a combination of closely related but separate theoretical concepts.



The relative consistency of the findings for a general sense of perceived personal control are perhaps more striking when considering the differences between samples in prognosis, the amount of control available to the patient over the condition, and the demands of treatment.

## 5. Locus of Control

As only two studies in the present review used a general locus of control measure, which was not the main control variable of interest, the results of studies incorporating general locus of control are discussed in later sections.

### 5.1 Health Locus of Control

Of the studies within the present review, nine explored the relationship between perceived control over general health and psychological outcomes using either the Health Locus of Control Scale (Wallston, Maides & Wallston, 1976) or Multidimensional Health Locus of Control Scale (Wallston et al, 1978).

Four of the nine studies were undertaken with samples of cancer patients. Marks, Richardson, Graham and Levine (1986) considered the role of health locus of control beliefs in relation to depression within the first week of cancer diagnosis. The results suggested that for patients with a high internal locus of control, who perceived their illness as severe, there was a considerably less depression, while patients who perceived little personal control or higher chance control experienced greater distress. Andrykowski and

Brady (1994) investigated the role of health locus of control in relation to psychological distress in bone marrow transplant patients. The study found no simple main effect for health locus of control and psychological distress. However, they found that internal locus of control was associated with greater distress when severity of illness was greater. Contrary to a threat matching hypothesis, internal locus of control was also related to greater distress when severity was low for those who had previous treatment failure. Powerful Others control generally appeared to be beneficial for those who had not previously failed cancer therapy, and had detrimental effects for those who had failed therapy and whose illness was severe. Lowery, Jacobson and DuCette (1993) investigated the role of causal attributions and control in adjustment to breast cancer. They found no significant main effects or interactions for health locus of control for any of the adjustment indices. However, feelings of loss of control since hearing about cancer diagnosis were significantly and negatively related to the adjustment indices. Perceived loss of control over one's body, health and emotions was major predictor of adjustment and a significant predictor of psychological distress. Friedman, Baer, Lewy and Lane (1988) also conducted a study with breast cancer patients examining a number of potential predictors of post-surgical (within the previous 10 years) psychosocial adjustment. Daily stress and expressed anger were found to account for almost half of the variance in psychosocial adjustment, but locus of control was not found to be significantly related to any of the adjustment scales.

Fowers (1994) examined the effect of perceived control on adjustment to cardiac illness, with a sample of cardiac rehabilitation patients. The results highlighted some mild, non-significant correlations, which suggested that an internal locus of control was beneficial under conditions of high life stress, and a Powerful Others locus of control was generally

detrimental. However, there was no significant relationship between perceived control and adjustment when demographic and illness variables were controlled for in the analysis.

Shelley & Pakenham (2007) examined the moderating role of external health locus of control appraisals for the effect of pre-operative preparation on distress for coronary artery bypass graft patients. When baseline distress was controlled for, the interaction between pre-operative preparation, external health locus of control and self-efficacy was significantly related to current distress and pain, and distress at discharge. When the patients' level of external locus of control and self-efficacy were matched, patients experienced less distress. However, when the patients' external locus of control and self-efficacy differed, pre-operative preparation led to increased distress (high external locus of control, low self-efficacy) or made no difference to outcome (low external locus of control and high self-efficacy).

Bremer (1995) considered the role of health locus of control for psychological adjustment for patients with End Stage Renal Disease across different treatment groups (haemodialysis, continuous ambulatory peritoneal dialysis (CAPD) and renal transplant). The findings suggested that the only significant association between health locus of control and adjustment was for the Chance scale, with low levels of Chance control associated with better mood and life satisfaction. Health locus of control was found to moderate the relationship between treatment modality and adjustment, such that those with Chance beliefs, who received CAPD or a transplant, were more likely to experience poorer adjustment at baseline and one year follow-up. Similar findings were obtained by Evans, Fernando, Rabkin and Fishman (2000) in a longitudinal study of HIV infected gay men. Of the locus of control variables, only Chance was found to be a significant predictor of depressive symptoms, hopelessness and stress.

Helgeson (1992) examined control over illness in relation to adjustment for cardiac patients following a first cardiac event. A large number of significant findings for control were reported. The main results of the study suggested that health locus of control was associated with less distress and better psychosocial adjustment at three months post discharge. In addition, personal feelings of control over illness (assessed by a single item) were associated with better psychosocial adjustment at three months post discharge. In general, feelings of personal and internal health locus of control were associated with better adjustment and/or reduced distress for the entire sample regardless of whether the patient had undergone surgery, had a poor prognosis, or had been re-hospitalised. Feelings of vicarious control (Powerful Others) were only related to better adjustment for patients who had undergone surgery.

The studies examining health locus of control beliefs for psychological distress or psychosocial adjustment found no significant main effects. While three of the studies found no significant results for health locus of control beliefs and adjustment, the majority of the studies highlighted a complex range of significant interactions. All of the studies used advanced statistical techniques to examine the relationships, employing regression and hierarchical multiple regression analyses. Interestingly, two of the studies that reported non-significant results (Friedman et al, 1988; Fowers, 1994), used the lowest sample sizes amongst these studies ( $n=67$  and  $n=71$ , respectively). It is questionable whether these sample sizes were sufficient for the statistical approaches employed and to examine moderational or mediational relationships. However, Lowery et al (1993) also found no significant results for health locus of control, despite having the largest sample ( $n=195$ ).

One of the studies that did not find health locus of control significantly related to adjustment was the study by Friedman et al (1988). In their study, Friedman et al (1988) used the Health Locus of Control Scale (Wallston et al, 1976), which assesses control in relation to an internal-external dimension. They suggested that the non-significant result for health locus of control might be related to the use of a general health measure of control, rather than a cancer-specific measure (Friedman et al, 1988). While Lowery et al (1993) did not find significant results for health locus of control, the findings for perceived control over specific aspects of health were significant. This finding supports suggestions that it may be beneficial to examine control at a specific rather than general level.

Although Marks et al (1986) suggested that there was little association between control and depression, some strong correlations were found for Self control and Chance control in relation to depression. The lack of any strong associations between Doctor control and depression could potentially be related to the stage of illness. As patients had only just received a diagnosis of cancer they had little opportunity for experiences of treatment, which may be necessary for beliefs in Doctor control to have an appreciable impact (Marks et al, 1986). It is perhaps worth noting that Marks et al (1986) selected only nine items from the MHLC (Wallston et al, 1978) scale, three for each subscale and combined the Chance subscale with three items from the I-E LOC scale (Rotter, 1966), making their results less directly comparable with other studies using the MHLC.

The studies by Andrykowski & Brady (1994) and Helgeson (1992) found different results for Internal locus of control. Andrykowski and Brady (1994) found that Internal control was associated with increased distress when illness severity was greater, while Helgeson (1992) found that Internal control was associated with better adjustment and/or reduced distress for the entire sample regardless of previous treatment, prognosis or rehospitalisation. This difference can perhaps be related to the nature of their samples,

Andrykowski & Brady (1994) study involved bone marrow transplant patients, while Helgeson's (1992) sample consisted of cardiac patients. Bone marrow transplantation is associated with significant risk, both for the operation and for delaying treatment (Andrykowski & Brady, 1994). The nature of this particular sample could also explain Andrykowski & Brady's (1994) unusual finding of higher distress in patients with an internal locus of control when disease severity (physical decline) was low. Perhaps, for these patients the decision to undergo transplantation in the absence of severe disease and previous failed treatments is more difficult (Andrykowski & Brady, 1994). In both of these studies the findings seem to suggest that the benefits of Powerful Other control are limited to those who have received successful treatment. The results of Shelley & Pakenham (2007) however, suggested that Powerful Other locus of control was only beneficial for patients who also reported high self-efficacy. It is worth noting however, that the patients in Shelley & Pakenham's study (2007) were pre-operative, and may have also lacked experience of treatment that might shape views about Powerful Others control. Andrykowski and Brady (1994) also found negative effects for Powerful Others control for those who had failed previous therapy and whose illness was serious.

Of the studies finding significant results, two studies only found relationships for Chance control (Bremer, 1995; Evans et al, 2000). In both studies Chance control was a significant predictor of psychological distress and poorer adjustment. The validity of generalised health locus of control measures when studying psychological adjustment amongst specific patient groups has been questioned (Watson, Greer, Pruyn & Van den Borne, 1990) and could potentially explain the reason for the limited findings.

## 5.2 Illness-Specific Locus of Control

There were five studies in the present review that utilised illness-specific health locus of control scales.

Watson et al (1990) examined the relationship between cancer locus of control and psychological adjustment, using the English version of the Cancer Locus of Control Scale (Pruyn, van den Borne, de Reuver, de Boer, Bosman, ter Pelwijk et al, 1988). The Cancer Locus of Control scale was found to have three dimensions: internal control over cause of cancer, internal control over course of cancer, and religious control. Locus of control was not found to be significantly related to anxiety or depression, although the authors noted that the rates of anxiety and depression in the sample were low.

Another study, examining psychological adjustment to cancer was undertaken by Sun and Stewart (2000). The study, which was undertaken in Hong Kong with a Chinese sample, used a translated version of the Multidimensional Health Locus of Control scale (Form B), which had been adapted to be specific to nasopharyngeal cancer. Sun and Stewart (2000) found that after controlling for neuroticism, Internal health locus of control was negatively associated with depression and GHQ scores, and Chance locus of control was positively associated with depression. Although both Internal and Chance control were found to contribute to predicting depression, when combined with social support, only social support quality made an independent contribution to predicting variance in psychological well-being.

Bremer, Haffly, Foxx and Weaver (1995) examined the relationship between an absence of control over health and psychological adjustment for End Stage Renal Disease (ESRD)

patients. Bremer et al (1995) found that locus of control was unrelated to well-being, but Chance control and illness intrusiveness were related to negative affect. After statistically controlling for treatment type and illness intrusiveness, locus of control was found to be unrelated to positive or negative affect. Most of the significant effects found in the study were for control over life dimensions, which were positively related to affect, satisfaction with life dimensions and well-being.

Talbot, Nouwen, Gingras, Belanger and Audet (1999) conducted a study examining the effects of illness intrusiveness and personal control on depression for a sample of French-Canadian diabetes patients. Control was assessed using the French version (Talbot, Nouwen & Gauthier, 1996) of the Internal Control scale from the Multidimensional Health Locus of Control Scale and a translated version of the Internal subscale of the Diabetes Locus of Control Scale (Ferraro, Price, Desmond & Roberts, 1987). Confirmatory factor analysis suggested that personal control, in part, mediated the relationship between diabetes intrusiveness and depressive symptoms. However, the authors chose to retain an alternative model which excluded personal control, as a better model to represent the data.

White, Lehman, Hemphill, Mandel & Lehman (2006) considered the roles of causal attribution and perceived control over Chronic Fatigue Syndrome (CFS) for psychological adjustment. The study found that Internal control did not correlate significantly with outcome, however, Powerful Others was correlated with depressive symptoms, anxiety and rumination. Interestingly, Chance control was correlated negatively with rumination.

Despite the use of illness-specific measures, three out of five studies found that health locus of control was not significantly related to outcome. The other two studies found that while health locus of control may play a part in accounting for depressive symptomology,



other factors such as quality of social support (Sun & Stewart, 2000) and illness intrusiveness (Talbot et al, 1999) may be far more important. Bremer et al (1995) suggested that health locus of control was less important than an overall sense of control over life in predicting psychological adjustment to ESRD.

Only the study by Sun and Stewart (2000) found any effect for Internal locus of control, which was significantly related to psychological well-being. For Powerful Others locus of control, only the study by White et al (2006) found a significant result, that being that a Powerful Others locus of control was associated with depressive symptoms, anxiety and rumination. This finding may be related to the fact that CFS is generally very poorly understood by the medical community, which most likely hinders effective treatment.

Two studies supported previous findings that Chance locus of control is significantly correlated with negative affect (Bremer, 1995; Sun & Stewart, 2000). Interestingly, White et al (2006) found that Chance control was associated with less rumination amongst CFS patients. The difference in these findings can perhaps again be accounted for by the differences in conditions (cancer and CFS). There is no clear etiology for CFS, although there are numerous theories. Previous studies have found that individuals who are unable to generate a causal explanation for their illness experience poorer adjustment (Lowery et al, 1993). White et al (2006) found that those who develop internally oriented causal explanations experience more depressive symptoms, anxiety and rumination. It is possible that for CFS patients, a belief in chance reduces the need to search for a causal explanation or generate internally oriented ones.

These findings provide very little evidence that perceived control over a specific health problem is of psychological benefit.

## 6. Personal Control over Aspects of Illness

The literature examining the role of control over aspects of health care is arguably the most complex. Numerous studies have assessed control over various aspects of illness, in a variety of combinations, using differing definitions and measures, with a range of different patient populations. The aspects of control studied include personal, vicarious and others' control over: daily symptoms; illness; future illness; disease progression; illness recurrence; consequences of illness; medical care; treatment; emotions; and decisions. In some studies some of these categories are assessed separately, and in other studies some categories are combined, making the delineation of the findings a difficult task.

Within this review 13 studies considered the relationship between control (over one or more aspects of illness) and psychological outcome. Five of these articles involved studies of cancer patients and generally consider similar aspects of illness; three articles involved patients with rheumatoid arthritis; two articles study perceptions of control over health amongst gay men with AIDS; and the remaining studies involved cardiac patients, and two different samples of older people: older people requiring post-hospital care and patients with Parkinson's Disease.

Thompson, Sobolew-Shubin, Galbraith, Schwankowsky & Cruzen (1993) conducted a study examining control over a number of aspects of illness in relation to psychological maladjustment amongst cancer patients. Elements of control included: control over emotions and physical symptoms; relationships; medical care; progression of disease; and control in general. The results suggested that there was a significant relationship between adjustment and each the four areas of control (control over emotions and symptoms,

relationships, medical care and disease progression) with control over emotions and physical symptoms accounting for most of the variance (46%). Although the individual dimensions of control over 'relationship with spouse' and 'medical treatment' were not correlated with adjustment. The findings suggested that participants with greater overall perceived control were significantly better adjusted, even when demographic variables were controlled for.

Jenkins & Pargament (1988) studied cognitive appraisals in cancer patients, examining the relationship between perceptions of current control over cancer (by self, other people, God, chance, natural causes) and psychological adjustment. They found only a limited number of significant correlations and control appraisal variables were only modest predictors of adjustment in terms of self esteem and behavioural upset. None of the control variables significantly predicted staff ratings of global adjustment. Higher levels of personal control were found to be related to lower pessimism and reactivity to threat. Perceptions of God control were associated with higher self-esteem and lower observed behavioural upset. High levels of perceived chance control were also associated with lower levels of behavioural upset.

Tomich & Helgeson (2006) considered the adaptive value of perceptions of personal control for a sample of women who had experienced a recurrence of breast cancer within a period of five years. The participants were individually matched (on a range of variables) with breast cancer patients who had not had a recurrence. Control over the 'future course of illness', 'day to day symptoms', and 'emotional responses to illness' were assessed using single items. For women who experienced breast cancer recurrence, perceived control over illness at baseline was associated with poorer physical and mental functioning and less benefit finding five years later. This finding was not the case for women who had

remained disease free, whose functioning was not reduced and who were able to find more benefit. Similar but non-significant trends were also found for perceived control over 'future disease course', and perceived control over 'emotional responses to illness'.

Carver, Harris, Lehman, Durel, Antoni, Spencer et al (2000) examined the relationship between the perception of control over the recurrence of breast cancer and distress in two samples of women with early stage breast cancer. The results of Study 1, suggested that those perceiving 'personal control over outcome' tended to be more optimistic about outcome. Neither personal control nor the interaction between control and outcome expectancy were significantly related to distress at any of the assessment points (pre-surgery, post-surgery, and 3, 6 or 12 months post-surgery). Study 2 examined the relationship between perceived control and distress, allowing a greater period for adjustment post-surgery, with a single assessment at 3, 6 or 12 months following surgery. The results replicated those found in Study 1, with no relationship found between personal control and distress.

Norton, Manne, Rubin, Hernandez, Carlson & Bergman (2005) considered the role of perceived control, as part of a study of psychological distress amongst ovarian cancer patients. The study found that participants with greater physical impairment (functional disability) perceived having less control over their emotional responses to illness and medical aspects of their treatment, and those with less 'control over treatment' reported greater psychological distress. The results suggested that patients' perceptions of control served as a mediator in the relationship between physical impairment and psychological distress (Norton et al, 2005).

Affleck, Tennen, Pfeiffer & Fifield (1987) in a study of rheumatoid arthritis patients examined the relationship between perceptions of personal control over 'daily symptoms', 'future course of illness', and 'care and treatment', and mood and psychosocial adjustment. In addition, they assessed perceptions of health care provider control over 'daily symptoms' and 'future course of illness'. The study found that patients who perceived greater personal control over symptoms and over disease course saw their illness as more predictable. Perceiving personal 'control over symptoms' was significantly associated with mood for patients with moderate and severe disease. While the perception that healthcare providers had 'control over symptoms', was significantly related to negative mood. Perceived control over disease course was significantly associated with negative mood and less positive adjustment in patients with severe disease severity. 'Control over treatment' was the only control variable unconditionally associated with mood and adjustment.

Chaney, Mullins, Uretsky, Doppler, Palmer, Wees et al (1996) examined the relationship between perceived illness control over daily symptoms, attributional style for negative events, and depression in a sample of rheumatoid arthritis patients. They found that under conditions of low perceived illness control, greater internal and global attributions for negative events were associated with increased depression. Under conditions of high perceived control, variations in causal attributions were unrelated to depression.

Schiaffino & Revenson (1992) looked at the moderational and mediational roles of perceived control over illness and depression with a sample of rheumatoid arthritis (RA) patients. In addition, self-efficacy beliefs and causal attributions (for a recent symptom flare) were considered. Perceived control was not directly related to depression, but was

related to causal attributions, and self-efficacy. Self-efficacy mediated a weak relationship between perceived control and disability. A similar but non-significant pattern was found four months later. Patients who perceived their illness as less controllable, and who made internal, global, stable attributions experienced greater depression at baseline.

Griffin & Rabkin (1998) looked at the relationship between perceived control and psychological adjustment for people with advanced AIDS. Control was assessed with single items to rate 'perceived control over illness'; to examine the most important consequences of illness; and to rate 'perceived control over the most important consequences'. The study found that participants reported greater feelings of 'control over the course of illness' than the most subjectively important consequences of illness (e.g. finances, decreased quality sex life, relationship problems with partner, friends and family, negative effects on appearance). The perception of 'control over day to day illness' was associated with less psychological distress, less hopelessness and fewer cognitive depressive symptoms. Individuals with low levels of perceived control and high levels of realistic acceptance reported the most hopelessness. Physical symptoms and 'perceived control over illness' were the only predictors of depression, accounting for 34% and 15% of the variance in depression, respectively.

Reed et al (1993) studied the effects of perceived control on global adjustment for gay or bisexual men with AIDS. They used single items to assess a number of aspects of control, including: locus of control; and personal and vicarious control over 'symptoms', 'illness' and 'medical care and treatment'. The study found that locus of control and personal control were both significantly related to global adjustment, at baseline and eight months later. Patients who perceived greater control over their illness experienced better adjustment, while the opposite was true for those who perceived that others controlled their

illness. Self-reported health status was significantly correlated with 'personal control over symptoms' and 'control over illness'. When health status was statistically controlled for, the relationship between 'personal control over illness' and better adjustment was non-significant. Controlling for locus of control, 'control by others over medical care and treatment' was significantly related to poorer global adjustment and negative affectivity. This relationship was maintained even after baseline global adjustment was statistically controlled for. When self-reported health status was considered, the correlations were found to be stronger for the low status group (except for 'personal control over illness course' and adjustment, which became non-significant) and non-significant for the high status group.

Michie, O'Connor, Giles & Earll (2005) conducted a study related to the psychological changes that predict health outcome following attendance at a cardiac rehabilitation course. Using a sample of cardiac rehabilitation patients, perceptions of control over illness (assessed using items from the Illness Perceptions Questionnaire; Weinman, Petrie, Moss-Morris & Horne, 1996) were examined as one of a number of factors related to changes in mood and quality of life. The results of the study suggested that an increased perception of 'control over illness' predicted lower depression, and there was a non-significant trend towards lower anxiety eight weeks after the course. However, increased self-efficacy (confidence in behaviour change) rather than perceived control predicted better mental health eight months after the course.

Coulton, Dunkle, Haug, Chow & Vielhaber (1989) considered the impact of decisional control on adjustment to post-hospital care for older people being discharged from hospital. They found that locus of control and 'control over care decisions' had no effect on psychological distress one month after discharge. However, individuals with high

internal locus of control, who perceived a lack of control over the decision about post-hospital care, experienced more distress. Those with more control over their discharge plan reported more satisfaction, although the interaction between decisional control and locus of control did not reach significance for 'satisfaction'. Individuals with greater external locus of control experienced less decisional anxiety. Decisional anxiety was associated with lower satisfaction.

Wallhagen & Brod (1997) examined the relationship between perceived control over disease progression and daily symptoms, in relation to well-being in a sample of patients with Parkinson's disease. Control over symptoms accounted for additional variance beyond that of disease severity. Despite almost equal ratings for perceived control over symptoms and control over disease progression, there was no relationship between control over disease progression and well-being.

As previously noted the findings for studies examining the role of control over different aspects of illness is extremely complex. The majority of studies discussed used single items to assess different aspects of control, which has implications for reliability. Most of the studies employed either regression or hierarchical regression analyses. However, the studies by Jenkins & Pargament (1998) and Reed et al (1993) only examined correlations, while Michie et al (2005) used Wilcoxon Signed Ranks for data analysis. The size of the samples used varied greatly between studies and may be related in some cases to the lack of significance of some findings.

The findings of these studies suggest that there are some benefits to perceived 'personal control', such as reduced pessimism and reactivity to threat (Jenkins & Pargament, 1988), and increased optimism (Carver et al, 2000). Reed et al (1993) found that locus of control



was related to current and future adjustment. Coulton et al (1989) found that when patients lacked decisional control, an internal locus of control was related to distress following discharge to post-hospital care. However, patients with an external locus of control experienced less decisional anxiety, with decisional anxiety related to poorer adjustment (Coulton et al, 1989). It has been suggested that the psychological impact of perceiving decisional control is dependent on the extent to which control is expected (Coulton et al, 1989).

Within the literature reviewed, it was not clear whether the term ‘control over illness’ was referring to ‘control over symptoms’, ‘control over disease course or progression’ or both. A number of studies examining ‘control over illness’ and ‘control over disease course/progression’ have found increased control related to better psychological adjustment (Griffin & Rabkin, 1998; Michie et al, 2005; Reed et al, 1993; Thompson, et al, 1993). Perceiving ‘control over illness’ has also been associated with more ‘benefit finding’ (Tomich & Helgeson, 2006). An exception to these findings appears to be in the circumstance of severe illness, in which case, greater control is associated with reduced mental and physical functioning, reduced benefit finding (Tomich & Helgeson, 2006), lower mood and poorer adjustment (Affleck et al, 1987). Some studies have failed to find a relationship between ‘control over illness’ and better psychological outcome. Carver et al (2000) found that ‘personal control over recurrence’ was not significantly related to distress. Schiaffino & Revenson (1992) did not find a direct relationship between ‘control over illness’ and depression, although they found an interaction between control and attribution style. Both Schiaffino & Revenson (1992) and Chaney et al (1996) found that patients with low perceived illness control, who made internal, stable, global attributions, experienced increased depression, and that this relationship did not exist for those with perceptions of high control. It should be noted however, that both of these studies

employed relatively small samples for hierarchical multiple regression analysis (n=64 and n=58, respectively).

Affleck et al (1987) found that increased control over symptoms was related to improved mood for patients with moderate or severe illness. They also found that patients who perceived health care providers as having control over their symptoms experienced lower mood. Although, Reed et al (1993) found that 'personal control over symptoms' was related to current and future adjustment, this relationship became non-significant when health status was controlled for statistically. It is perhaps worth noting, that the sample in the study by Reed et al (1993) consisted of only 24 participants, and may have lacked statistical power. Thompson et al (1993) combined the dimensions of 'control over symptoms' with 'control over emotions', finding a significant relationship with adjustment. Tomich & Helgeson (2006) examined 'control over symptoms' independently, obtaining similar but non-significant findings to those for they obtained for 'control over illness'.

Studies examining 'control over medical care and treatment' have generally found similar results, suggesting that increased control is related to improved adjustment (Thompson et al, 1993; Affleck et al, 1987), mood (Affleck et al, 1987) and satisfaction (Coulton et al, 1989). Interestingly, Thompson et al (1993) found a significant relationship with adjustment for 'control over care' but not for 'control over treatment'. Norton et al (2005) suggested that 'control over treatment' mediated the relationship between physical impairment and disability. Studies have also shown that an absence of 'control over care/treatment' is related to increased distress (Norton et al, 2005); and perceiving others to have control is related to reduced adjustment and negative affect (Reed et al, 1993). Coulton et al (1989) found that decisional control relating to post-hospital care was not related to psychological distress one month after discharge. It is worth noting that 90% of

the sample felt that they had at least some control over the decision, 60% were discharged either to their own or a relative's home, and the rates of distress amongst participants were low (Coulton et al, 1989).

## 7. Discussion

The present review has shown varied findings for the relationship between perceived control and positive psychological outcomes. The studies reviewed seemed to indicate that a sense of personal control (at a general level) is related to favourable psychological outcomes, despite differences between the populations studied. The studies examining health locus of control beliefs found no main effects, although a number of these studies found significant interaction effects. This finding suggested that perceived control might moderate or mediate the effect of other variables on outcome. The findings of the studies within this review that used illness-specific measures of control provided little evidence that perceived control is of psychological benefit. The findings for 'control over illness' and 'control over disease progression', largely suggested that greater perceived control is related to better psychological adjustment. However, other studies have failed to find significant results for 'control over illness', even with relatively large samples (Carver et al, 2000). There is general indication that 'control over symptoms' is of psychological benefit, with a number of studies finding significant or close to significant relationships with mood and adjustment. It has been suggested that control over symptoms, may have the greatest effect on adjustment, as symptoms may be more amenable to control than disease severity (Affleck et al, 1987). The findings for 'control over treatment' have also fairly consistently found a relationship between perceived control (or lack of it) and

adjustment. In one study, 'control over treatment' emerged as the only control predictor unconditionally associated with mood and adjustment (Affleck et al, 1987).

In evaluating these findings, there are a number of conceptual and methodological issues to consider. As previously noted, the conceptualisation of control has been problematic in terms of developing a coherent body of literature. The studies by Arnold et al (2006) and Barez et al (2007) both used conceptualisations of control that included self-efficacy. Carver et al (2000) suggested that combining the concepts of perceived control and perceived efficacy would confound results. Schiaffino & Revenson (1992) suggested that although the interactional patterns of control and self-efficacy are similar, they are conceptually distinctive.

In the present review, an attempt has been made to address the issue of generality and specificity, and to consider the findings in relation to different aspects or dimensions of control. It is interesting to note, that despite calls for the use of specific illness measures (Watson et al, 1990; Friedman et al, 1988), studies employing these measures failed to find any significant results for perceived control. The issue of how control is assessed has been touched upon throughout. The studies within the present review that used standardised measures, reliability coefficients between 0.7 and 0.9 were usually reported. The issue of measurement reliability becomes more problematic when idiosyncratic measures are employed. Most of the studies examining 'control over aspects of illness' used single items to assess aspects on control, which may make the results of these studies less directly comparable and potentially less reliable.

A number of the reviewed studies employed correlational designs, particularly those considering 'perceived personal control'. Correlations can only establish a relationship

between variables, but can not determine the direction of causality or reciprocal effects. The majority of the studies examining ‘health locus of control’ and ‘control over aspects of illness’ used more robust statistical techniques.

A methodological issue requiring consideration is the particular nature of the health condition of the populations studied. The prognosis (actual severity), perceived severity, perceived threat, symptom severity, chronicity, predictability and intrusiveness of the illness may all influence how control relates to outcome. Other influential factors might also include social knowledge and attitudes about the health problem, and social and personal contexts (Wallhagen, 1998). Some of these factors and their relationship to perceived control have been considered within the studies, however defining and measuring each of these influences reliably poses a significant challenge to researchers. A similar problem exists in relation to the definition and measurement of outcome. A variety of outcome measures have been employed in the presented studies, although it is beyond the scope of this review to consider them in any depth. Many of the studies have utilised established standardised measures, often used in combination, sometimes standardised and combined in composite indices, and sometimes abbreviated or adapted. Even when outcome is similarly defined, whether the use of different measures would produce comparable results is unclear.

Almost all of the studies reviewed focused on specific patient groups, often very narrowly defined, most likely in the attempt to refine the assessment of perceived control and minimise potential confounding variables. However, what this arguably produces is findings that are limited in their generalisability. What has been attempted within this review and could potentially be valuable, is considering the factors that apply more generally to wider groups of patients, as well as considering the specific factors. In

addition, future research that focuses on determining what aspects of control are useful, for which patients, and at what point in their care, could facilitate a range of interventions aimed at developing perceptions of control in patients that could be of psychological benefit. Such interventions might include, pre-diagnosis counselling, patient education initiatives, and end of life care planning.

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## Appendix 1

### Search Strategy

## Search Strategy

**Databases:** PsycINFO (through EBSCO HOST)  
PsycARTICLES (through EBSCO HOST)  
SCOPUS  
Web of Science  
Cochrane Database

### Search Terms:

Control search terms:

Perceived control, personal control, decisional control, control over treatment, locus of control, control appraisal and appraisal of control

Benefit search terms:

Well being, adjustment, coping, quality of life, distress, and benefit

Health Care search terms:

Health care, illness and patient

N.B.

The decision was made not to search using the term 'health' as this term is too broad and generated a large number of results, which were predominantly irrelevant for the present review.

### PsycINFO and PsycARTICLE searches

**Search terms in:** abstract

**Limited to:** Adult population, all journals, English, and excluding book reviews and dissertations.

### SCOPUS and Web of Science searches

**Search terms in:** separate searches for each term in title and in the title, abstract and keywords.

**SCOPUS searches were limited to the subject areas:** psychology, medicine, nursing, health professions and social sciences.

**Web of Science searches were limited to:** English and articles.

## Cochrane database searches

**Search terms in:** title, abstract or keywords

**Selection criteria:** Adult population (aged 18 or above)  
Clinical sample/patients (excluding student samples, families, carers, staff, and non-patients)  
Physical health problems (excluding mental health and learning disabilities).  
Specific reference to the psychological benefits of a person perceiving a sense of control over some aspect of their health or health care.

N.B.

A search of the Cochrane database did not result in any relevant reviews or articles.



**Part Two:**

**The Development of a Scale to Assess Attitudes to Advance Statements**

## 1. Abstract

The study aimed to develop a valid, reliable and acceptable scale that could be used to assess attitudes to Advance Statements amongst people over 50 years old.

Scale items were developed following an analysis of themes present in the literature on Advance Statements, Living Wills and Advance Directives. The 10 most prominent themes were each represented by four items, leading to a 40-item scale. This was piloted with 46 people, who provided written feedback. From the pilot sample, six participants were recruited for a focus group to gain in-depth feedback. Based on the findings of the pilot and focus group, the scale was amended and distributed to 495 people. A total of 189 responses were received, 180 of which were sufficiently complete for use in subsequent analysis.

Three of the 40 initial items were removed following an analysis of discriminatory ability, assessed using multiple Mann Whitney U-Tests. The internal consistency of the 37-item scale, assessed using Cronbach's alpha, was 0.861. The scale was then subjected to principal components analysis using varimax rotation. A two component solution accounting for 37% of the total variance was accepted for the final scale on the basis of clarity and interpretability. Items that did not load significantly on either component or above 0.4 were removed (Field, 2005). This resulted in a 28- item scale with an alpha of 0.862 and split-half reliability of 0.890.

The scale has potential clinical application in the facilitation of discussions about end of life issues and care planning; in clinically applied research; and in service development and evaluation. The generalisability of the scale and factor structure to clinical populations needs to be determined. The scale also requires use in further research to establish validity and temporal stability.

## 2. Introduction

The inevitable process of aging is one that usually involves a decline in aspects of health and functioning, the negative effects of which are not easily amenable to control (Thompson *et al*, 1993). Although conceptualisations of control have varied across studies, the majority of literature has defined control in relation to amount of influence that individuals believe they have over desired outcomes (Wallhagen & Brod, 1997). Common to theories that encompass the concept of control is the general belief that control is related to better psychosocial and physiological states (Wallhagen, 1998). A considerable body of research has suggested that perceived control is associated with multiple positive outcomes including emotional well-being, more successful coping and adjustment, better health and reduced mortality (Wallhagen, 1998).

A compensatory model suggests that when control in one area of life is not attainable, a person can compensate by feeling efficacious in other areas in order to maintain perceptions of control (Baltes & Baltes, 1986 cited in Thompson *et al*, 1993). One area over which patients can realistically and adaptively exercise personal control is treatment decision making (Reid, 1984 cited in Affleck *et al*, 1987). Affleck *et al* (1987) found that control over medical treatment was a significant factor for psychological adjustment for patients with cancer. Their results supported Reid's (1984) hypothesis of participatory control, which suggests that active, collaborative patient involvement in care planning is optimal for chronic disease (Affleck *et al*, 1987). Yet, medical care typically restricts control and historically paternalistic attitudes have often resulted in physicians making treatment decisions for their patients, with patients rarely advised of alternatives (Reed *et al*, 1993). Numerous studies have highlighted that given the potential benefits of perceived control, it is important to consider the ways in which a sense of control might be promoted.

One possibility for increasing people's sense of control over their future health care and treatment decisions might be the use of Advance Statements.

## 2.1 Advance Statements

Advance Statements (formerly known as Living Wills) are statements made by a person, while they have capacity, that specify how they would want medical decisions to be made if they were to become incapacitated (Hagelin *et al*, 2004). More broadly, an Advance Statement can be defined as a record of a person's views, values, and preferences for future medical treatment and care (Help the Aged, 2006). Advance Statements may include instructions for refusing treatment, known as Advance Directives. However, an Advance Statement cannot instruct a doctor to deny basic care, act against their clinical judgement, or do anything that is unlawful, including the practise of euthanasia (Help the Aged, 2006). An Advance Statement can be made in writing, as a witnessed oral Statement, or at the patient's request, as a record of a discussion with a doctor within their medical file (Help the Aged, 2006). An Advance Statement will only come into effect when the particular circumstances specified within the Statement are met, and the person is no longer able to make a decision or express their preference due to physical or cognitive incapacitation.

Currently in the UK, Advance Statements that specify the type of care and treatment a person would like to receive are not legally binding, but should be used to guide treatment decisions (Help the Aged, 2006). However Advance Directives refusing treatments are legally binding, providing at the time they were made the person had capacity and understood the broad consequences of the decision, and that the circumstances specified in the statement apply to the current situation (Mental Capacity Act, 2005).

## 2.2 Arguments in Favour of the Use of Advance Statements

One of the most prominent arguments in support of the use of Advance Statements is their suggested potential to enhance personal autonomy and protect the rights of the dying person to self-determination (Beauchamp & Childress, 2001). It has been argued that Advance Statements enable a patient to influence medical decision-making (Burchardi *et al*, 2005) and can act as a vehicle for patient advocacy, giving patients control in their lives when they can no longer exercise autonomy directly (RCN, 1994). Rashid (2000) argued that the use of Advance Statements represents a fundamental shift away from paternalistic care towards a paradigm of patients taking greater personal responsibility for their health.

It has been argued that Advance Statements have the potential to enhance communication about end of life care and in doing so, help to guide treatment. It has been proposed that making an Advance Statement can help people to discuss death and dying with their doctor (Fagerlin & Schneider, 2004), and provide an opportunity for an informed dialogue between healthcare professionals and patients (Sommerville, 1995). Roberts (2001) suggested that having an Advance Statement makes it more likely that a patient will discuss their wishes for future care and treatment with doctors and relatives, and therefore more likely that the person's wishes will be followed. Others have contended that Advance Statements can help to guide doctors in making care decisions for patients who lack capacity (Burchardi *et al*, 2005; Widdershoven & Berghmans, 2001).

Advance Statements have been viewed as a means of protection: against treatments that a person is sure they would never want; from treatment that may be against a person's religious beliefs (Roberts, 2001); and from relatives who may misunderstand the person's wishes, disagree about treatment or place their own needs above those of the patient (Help

the Aged, 2006). Burchardi *et al* (2005) found patients believed that Living Wills could prevent a person from having to receive life-sustaining treatment when remaining quality of life is drastically diminished and there is no chance of improvement.

Advance Statements have also been viewed as a useful way of preparing for future illness and decision making (Seymour *et al*, 2004). Roberts (2001) suggested that Living Wills encourage people to consider their priorities and the kind of life and death that they want. Sypher (2002) argued that creating an Advance Statement might help to avoid extra stress at the time of hospitalisation when the emotional and physical strain of trauma or serious illness might make it very difficult to make rational decisions which may have complex implications.

### 2.3 Arguments Against the Use of Advance Statements

One of the strongest arguments against the use of Advance Statements is in relation to their validity. Some authors have suggested that Advance Statements are invalid in their construction and represent views that may change over time and with changes in circumstance, increasing disease or disability (Rashid, 2000), or in light of advances in medical treatments (Roberts, 2001).

Advance Statements may be regarded as problematic because they contain a judgement about a situation that one cannot really know or fully anticipate (Widdenshoven & Berghmans, 2001). As Advance Statements are written in anticipation of future circumstances, it has been disputed that it is possible to adequately predict the nature of a future condition (England, 2004; Welie, 2001), know whether a condition is reversible or

the timing of the end of life (Benner, 2003). In addition, the circumstances at the end of life may be very different to those that a person had anticipated and planned for within an Advance Statement (Roberts, 2001). It has been argued that many people do not know enough about their illnesses and treatments to make life or death decisions about them (Fagerlin & Schneider, 2004). It may not be possible for patients to be fully informed of treatment options when making an Advance Statement, given that medical technology is constantly advancing. Interventions which may prolong life and improve quality of life may become available in the future, which could alter a patient's preferences (England, 2004; Roberts, 2001).

Roberts (2001) argued that a change in circumstance may lead to a change in perspective and what a person actually wants when facing death may not be what they anticipated wanting. When a person is healthy they may not be able to imagine that they could bear to live with severe limitations or undergo intensive or invasive treatments (Benner, 2003; Roberts, 2001). It has been suggested that what might seem unacceptable in good health may later be actively requested (Rashid, 2000), and that people underestimate desire for medical treatment should they become ill (Ryan, 1996). Fagerlin and Schneider (2004) argued that in face of serious illness, people are willing to accept a much reduced quality of life in preference to death. Schwartz (2005) suggested that in the face of serious illness and impending death there is a 'response shift', such that people abandon their usual roadmap of values and adopt new perspectives. Robertson (1991) stated that while Advance Directives offer a sense of control over the future, they reflect the values and interests of a person while they are competent but not their interests when they become incompetent and are in a radically different situation.

In contrast to the emphasis on patient autonomy, others have argued that decisions about end of life care should be made in consensus with the patient, physician and family, as the decision to continue or discontinue treatment has a powerful and lasting effect on all those concerned (Burt, 2005). Murray and Jennings (2005) stated that dying is not the sole concern of the person who is dying but of all those related to that person. Some believe that while Advance Statements can give an indication of patients' values, doctors should retain the responsibility for medical decision making (Widdenshoven & Berghmans, 2001). That an Advance Statement cannot instruct a doctor to act against their clinical judgement, and requests for treatment and care are not legally binding, adds support to the view that end of life decisions should be made by doctors. Welie (2001) argued that Living Wills are either too specific to be honoured or not specific enough to be of any use, and should be used to supplement best interest judgements. Sommerville (1995) argued that for the practical purposes of providing appropriate care, a designated surrogate decision maker is preferable to almost any form of Advance Statement, a position also adopted by Fagerlin and Schneider (2004). Some studies have found that older people may prefer or expect to trust their family to express their wishes or make care decisions on their behalf (Help the Aged, 2006; Seymour *et al*, 2004). However, healthcare proxy decisions made on behalf of patients may often be an inaccurate substitute for patients' wishes (England, 2004), even when patients have discussed their wishes with their next of kin (Shalowitz *et al*, 2006) and may be more highly related to spouses' preferences than patients' (Pruchno *et al*, 2005).

Contrary to claims that Advance Statements enhance communication, others have argued that Advance Statements do not improve or facilitate doctor-patient communication about end of life issues (Laakkonen *et al*, 2004), help doctors and family to predict patients' preferences (Fagerlin & Schneider, 2004) or ensure that patient wishes about end of life care are followed (Roberts, 2001). Burchardi *et al* (2005) found little evidence of



Living Wills enhancing communication and suggested that good patient-physician communication is a prerequisite for end of life discussions. It has been suggested that doctors may listen to the wishes of the family more than those of the patient (Fagerlin & Schneider, 2004). It has also been suggested that even when patients have written Advance Statements that they do not affect doctors' behaviour and patient treatment (Fagerlin & Schneider, 2004; Widdenshoven & Berghmans, 2001) or have only a limited effect (Hickman *et al*, 2005). The extent to which Advance Statements are able to guide treatment has also been questioned on the basis that Advance Statements require interpretation and therefore cannot replace decision making or rule out doubts about what should be done (Widdenshoven & Berghmans, 2001).

While some have viewed Advance Statements as offering protection to patients, a number of authors have suggested that Advance Statements pose a significant risk. Sommerville (1995) argued that there is a risk in refusing life prolonging treatment, while Ryan (1996) went further, suggesting that making an Advance Directive is like betting with your life that life would not be worth living if you were to become seriously ill. Numerous authors have noted that Advance Statements require interpretation (e.g. England, 2004; Roberts, 2001; Widdenshoven & Berghmans, 2001), which inevitably involves the potential risk of the patient's wishes being misinterpreted (Roberts, 2001), or the Advance Statement being misunderstood or misused (Mirarchi, 2006). Sahm *et al* (2005) suggested that people feared the risk of being pressured into writing an Advance Directive and Advance Directives being abused by relatives.

A further argument against or barrier to the use Advance Statements is the belief that older people may be unwilling to discuss their preferences concerning end of life care (Laakkonen *et al*, 2004). Burchardi *et al* (2005) found that physicians believed that

patients associated Living Wills with imminent death and expected patients to be alarmed if approached about Living Wills (Burchardi *et al*, 2005). Burt (2005) argued that death is incomprehensible and that people do not want to talk about the reality of impending death. It has been suggested that there is a natural tendency to avoid conversations about death and dying (Sypher, 2002) and that most people resist facing up to their eventual death (Callaghan, 2005). It seems likely that death anxiety, denial (Rousseau, 2003) and avoidant coping styles may result in people being more reluctant to consider or discuss future health care needs and preferences.

#### 2.4 The Views of Older People

One of the few studies conducted considering the views of older people about Advance Statements was conducted by Seymour *et al* (2004). They ran a number of focus groups to consider the views of older people about a range of end of life issues, including Advance Care Statements and the role they might play in end of life care decisions. The study highlighted the view of the potential benefits of Advance Statements in aiding personal integrity and reducing the perceived burden of end of life decision making, but also anxieties about the misuse of Advance Statements, their future applicability and the possibility that preferences might change over time. In addition, although older people believed that advance care planning was important, 'participants reported worries and difficulties related to thinking about and discussing death and dying' (Seymour *et al*, 2004, p.57). Seymour *et al* (2004) found that older people perceived reluctance by others, in particular family members, to talk about death and dying. While experiences of bereavement across the life span can influence attitudes to death (Neimeyer *et al*, 2004), the experience of serious illness (in oneself or close others) or the death of a spouse or

close friends can prompt greater consideration of the issues of death, dying and end of life decision-making (Seymour *et al*, 2004).

A consistent theme within the findings of Seymour *et al* (2004) was the importance of relationships with family members and health care professionals. There were varying expectations about the extent to which family members could be relied upon and would be involved in the decision-making process (Seymour *et al*, 2004). The quality of family relationships was therefore seen as an important factor in the need for Advance Care Statements or the extent to which the family would be involved in end of life decision-making. The role of healthcare professionals and doctors in advising patients and their families about decisions, and the quality of the relationship and interaction were also seen as important.

## 2.5 The Role of Advance Statements in Healthcare

It could be argued that there is an increasing role for the use of Advance Statements in healthcare. Death is now most likely to occur at the end of a long life, and cognitive impairment and severe disability may make it impossible to ascertain with any accuracy the views and wishes of the older person about their care. The General Medical Council (2001) and British Medical Association (2001) have published guidelines suggesting that it is good practice to involve dying people and their families in care decisions. Late life planning has been associated with higher ratings of well-being (Floyd, Platz & French, 2004). Standard Two of the National Service Framework for Older People (DOH, 2001), which is focused on person-centred care, explicitly states the expectation that older people

should be treated as individuals, listened to, treated with dignity and respect, and allowed to make informed choices about their care.

Many people have suggested that Advance Statements should be viewed as part of a process of discussion over time rather than as a product (Crane *et al*, 2005; Help the Aged, 2005; Seymour *et al*, 2004; Sypher, 2002). It has been argued that this should be a collaborative process between doctor, patient (Burchardi *et al*, 2005) and family (Burt, 2005; Crane *et al*, 2005) because of the social nature of death (Burt, 2005; Murray & Jennings, 2005). It has been suggested that patients need to be supported to make their own decisions and have appropriate help to do so (Barker, 2004; Help the Aged, 2005), and that health professionals should initiate conversations and facilitate end of life planning (Forbes *et al*, 2000; Hickman *et al*, 2005) to encourage patients to participate in care decisions as fully as possible (Barker, 2004).

However, to date there has been little empirical research in the UK that explores public perception of Advance Statements and little is known about the willingness of older people to accept the idea of writing an Advance Statement (Sahm *et al*, 2005). With an ageing population and a growing interest in Advance Statements (Widdershoven & Berghmans, 2001), it seems that research considering the views of older people would be valuable.

The benefits to the NHS of research examining the attitudes of older people to Advance Statements could include highlighting a role for staff training, areas for service development (e.g. pre- and post- diagnostic counselling and end of life care) and helping to identify patients who would benefit from discussing end of life issues, thereby increasing service user well being, empowerment and satisfaction with services.

The aim of the current study was to develop a valid, reliable and acceptable scale to assess attitudes to Advance Statements amongst people aged over 50 years old.

### 3. Phase 1 Method

#### 3.1 Design

The study employed a non-experimental, correlational, two phase design using independent samples.

#### 3.2 Participants

Phase 1 of the current study involved an independent sample of English speaking people aged 50 years old and over. The pilot sample consisted of responses from 50 people (Bowling, 1997); however only 46 of these responses were sufficiently complete to be used. A further four responses were received after Phase 2 data collection had begun and so were not included. A proportion of the sample (31 out of 90 approached) was recruited from a database of older people willing to be approached about psychological research, held by Birmingham University. Additional participants were recruited through opportunistic sampling, which involved providing friends, family and colleagues with questionnaire packs that were cascaded to their friends, families and colleagues for independent completion and postal return.

The pilot sample consisted of: 11 participants aged 50-59 years old (45% female); 17 participants aged 60-69 years old (76% female); and 13 participants aged 70-79 years old

(46% female). Three participants (2 men and 1 woman) did not indicate their age. Two participants neither indicated age or gender. There were no participants in the sample that indicated that they were aged 80 years old or over. (See Appendix 3 for demographic information).

From the pilot sample, a focus group was recruited by inviting participants approached through the Birmingham University database. Eight people opted-in to the focus group, with six attending. The focus group comprised three men aged 59, 73, and 74 years old and three women aged 59, 70 and 79 years old, respectively (see Appendix 4 for consent form).

### 3.3 Measures

The current study utilised two measures, both constructed for the purposes of the study: the Attitudes to Advance Statements Scale, which was under construction as part of the study and is described below (see Appendix 5); and a demographic information sheet entitled: 'Information about You', which considered variables that might be relevant to attitudes to Advance Statements (see Appendix 6).

### 3.4 Procedure

#### 3.4.1 Scale development

The development of the scale involved a number of steps, based on the approach suggested by Goddard III and Villanova (2006). In creating the scale the Principal Investigator needed to determine the form that scale items and response formats should take in order to obtain the desired information. This involved the careful development of attitude statements that each addressed a single subject, did not bias the respondent to answer in a particular way, and were able to distinguish between respondents with different attitudes. The response format needed to allow respondents to answer in a way that they felt represented their views, including a response option that enabled respondents to indicate that they were unsure. Response options needed to be adequately comprehensive and discreet.

The scale items were developed using the research literature on Advance Statements, Advance Directives and Living Wills, in particular, but not exclusively, the work conducted by Seymour *et al* (2004). Seymour *et al* (2004) conducted a number of focus groups with older people exploring attitudes towards Advance Statements, identifying themes around the benefits of Advance Statements (e.g. to aid personal integrity and reduce the perceived burden on families) and concerns about the potential difficulties (e.g. the misuse of Advance Statements, their future applicability, the possibility that care preferences might change and difficulties relating to discussing death and dying). The study also highlighted discourses around the role of families and health professionals in end of life decision-making.

The first stage in developing the scale items involved an analysis of the key ideas and arguments within the literature, which were identified and labelled. These arguments were then reduced to fifty-three broad themes, by systematically examining each of the identified arguments and generating a new theme when arguments could not be mapped onto themes already generated. These broad themes were then reduced to thirteen themes, which included 60 sub-themes to minimise overlap whilst ensuring comprehensive coverage of the topic area. Statements were then created by the Principal Investigator for each of the 60 sub-themes using statements from literature, including the study by Seymour *et al* (2004). Once the statements were generated, they were checked to ensure that they were not leading, using double negatives or jargon, that they were not too long, complex, double-barrelled, or ambiguous, and to ensure that response options were appropriate and alternatives were specified where needed. In addition, the Principal Investigator considered the meaning of ‘strongly agree’ and ‘strongly disagree’ responses for each statement to ensure that participants’ responses would be meaningful and would give an indication of their attitude towards Advance Statements.

In developing the scale, it became apparent that it would be difficult to generate scale items that could be considered as simply being ‘in favour’ or ‘against’ Advance Statements as a whole. This led to the generation of 10 subscales, five of which had been proposed in the literature as arguments for Advance Statements (autonomy; protection; aiding communication of preferences; guiding treatment; and preparation for the future) and five of which would be in opposition or a barrier to Advance Statements (the view that doctors should make care decisions; Advance Statements pose a risk to patients; preferences expressed in Advance Statements are not valid or stable over time; family or surrogate decision makers are preferable; and not wanting to think about death and dying). Although the literature has frequently considered the role of healthcare professionals, items



addressing this aspect were not included because they did not enable an understanding of a persons' attitude to Advance Statements.

### 3.4.2 Pilot scale

In order to obtain a sample of 50 responses, 90 questionnaire packs were sent out based on an estimated response rate of 60%. The response rate was expected to be higher than usual response rates of 20-30% for postal questionnaires (Alreck & Settle, 1995; Bourque & Fielder, 2003) due to participants being approached by someone they know rather than receiving the scale by post. The pilot scale comprised 40 statements, four for each of the 10 'subscales', 20 of which were reversed scored to avoid response set. The scale required participants to respond to all statements and did not require the participant to skip any items. The statements were arranged to increase in sensitivity but appear relatively randomly from each subscale (Oppenheim, 1992). The scale utilised a five-point Likert scale with labels for each response for each item (strongly agree, agree, unsure, disagree, strongly disagree). This response format was based on the findings of Catt *et al* (2005), who piloted a number of different response formats for the development of an attitude scale about end of life issues to be used with older people. It was suggested that this response format is the simplest and most appropriate for an attitude scale to be used with older people (Catt *et al*, 2005). Two versions of the scale were created with different response formats. In one response scale the 'unsure' response was positioned as the central response option, while in the other response scale the 'unsure' response was positioned on the right after strongly disagree. These response formats were piloted to determine which would lead to the best response rate and lowest number of 'unsure' responses. An additional response option 'I prefer not to think about it' was also included

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to determine whether any of the statements were unacceptable or distressing. The front page of the scale included a brief summary about Advance Statements, instructions for participants and examples of how to respond, which were assessed for readability using the Flesch Reading Ease score, obtained using Microsoft Word software.

Included in the questionnaire pack was a Participant Information Sheet (see Appendix 7) that explained the study and provided some basic information about Advance Statements; and a demographic sheet 'Information about You', which included variables that might be related to attitudes to Advance Statements, in addition to basic demographic information. The Participant Information Sheet was developed based on guidelines produced by the University of Leicester and published on the COREC website. Each section of the information sheet was assessed for readability using the Flesch Reading Ease score, obtained using Microsoft Word, to maximise readability.

A feedback form (see Appendix 8) was also included in the questionnaire pack to evaluate how participants felt about completing the scale; whether any of the statements were distressing; if the layout was easy to follow; whether the instructions and statements were clear and understandable; if any aspect of the topic was not addressed; if the response options were adequate to express their views; if there was any difference between personally worded or generally worded statements; or if there was anything that could be done to improve the scale.

### 3.4.3 Focus group

In addition to piloting the scale, the Principal Investigator conducted a focus group with six of the pilot group participants recruited through the database held by the University of Birmingham. The participants were invited by a letter included in the questionnaire pack to opt-in to attend a focus group on a specified day, at a specified time to be held at Birmingham University. The focus group was 90 minutes in duration. A £10 gift voucher in addition to up to £5 for expenses was paid to focus group participants as a ‘thank you’ gift for attending. Using an interview schedule (see Appendix 9) developed in consultation with clinicians experienced in end of life issues and research methodology, the group was used to assess: the acceptability and comprehensibility of the scale and the individual items within it; the comprehensibility and sufficiency of the participant information and instructions; the adequacy of the response format; and elicit suggestions for improvements. The focus group was facilitated by the Principal Investigator, who took notes during the group and audio recorded discussions for the purpose of review. The recording was not transcribed. During the focus group the Principal Investigator checked back with participants to ensure that their comments had been understood.

## 4. Phase 1 Results

Given that both the pilot study and focus group were conducted for the purposes of assessing and improving the scale, information and instructions, the results for both are considered below (see Appendices 10 and 11 for summaries of feedback).

Of the 90 questionnaire packs distributed, 46 were returned within the deadline and completed sufficiently to be analysed. A total of 28 scales (of 45 distributed) were

returned in which 'unsure' was the central response option and 18 scales (of 45 distributed) were returned with 'unsure' after 'strongly disagree'. Chi-squared analysis suggested that the difference in return rate (based on response version) was not significant,  $\chi^2 = 2.174$ , 1 d.f., exact sig. (2-tailed) = 0.184.

The number of 'unsure' responses based on the response version was compared using a Mann-Whitney U Test, as visual inspection of a histogram suggested that the data was not normally distributed. The response versions ('unsure' as the central response option (mean = 9.96, median = 10, range = 20) and 'unsure' after 'strongly disagree' (mean = 8.33, median = 7.50, range = 21)) did not differ significantly in terms of the number of 'unsure' responses,  $U = 212.00$ , Exact sig. (2-tailed) = 0.373, ns,  $z = -0.903$ ,  $r = 0.133$ .

Some of the focus group stated that the scale included too many statements and too many response options. It was suggested that 'unsure' should be in the centre as this was more logical than having it at the end. Only four of the 46 respondents (9%) used the 'prefer not to think about it' response option, with the four participants using the response option one, two, four and nine times respectively, in response to 14 different questions. This suggested that the presence of the 'prefer not to think about it' option was not required by the majority of respondents. Seven of the 46 (15%) had one or more (range 1 to 3) missing responses, including one participant who also used the 'prefer not to think about it' option. As a result of these findings and suggestions, the response option 'I prefer not to think about this' was removed and 'unsure' was positioned as the central response option.

The pilot study included a feedback sheet to evaluate the scale, and identify difficulties and areas for improvement. The feedback sheet also enabled participants to make

additional comments. The majority of participants stated that they felt 'ok' completing the scale and none of the respondents indicated that they were in anyway distressed by completing the scale or responding to any of the statements. Some participants indicated that the scale was thought-provoking and interesting. Focus group participants reported that the scale was not upsetting or distressing, but they found it thought provoking and it prompted considerable discussion.

Only two participants stated that they found the layout difficult to follow. The majority of participants found the response options to be adequate, however six participants felt that the response options were not entirely sufficient, with a couple of participants stating that they wanted to qualify some responses and one stating that 'ticking boxes does not generally get it quite right'. Focus group participants also commented on wanting to qualify responses and a number of statements were highlighted by the group as problematic, unclear or difficult to answer. It was felt that some of the difficulties might be resolved by improving statement wording to increase clarity and reduce ambiguity, but that it was necessary for such a scale to retain the Likert scale response format for ease of administration and scoring.

Six participants found at least some of the instructions unclear or difficult to understand. The focus group discussion provided suggestions for improvements for the instructions on the scale, leading to the inclusion of more information about Advance Statements on the instruction page of the scale. Focus group members asked for respondents to be given only one option for how to respond (circling or ticking, whichever was the most common, but not both). As a result the instructions were amended to direct respondents to circle the most appropriate response option. Although the necessity of having written responses for each statement was questioned by one focus group member, other members felt that this

format was clearer than having headed columns or numbers, particularly for older, older people.

The majority of respondents (31 out of 46) indicated that the statements were clear and understandable. However, the feedback sheet and focus group highlighted a number of statements that participants had found unclear or difficult to answer and this information was used to make improvements to statement wording prior to distribution to the Phase 2 sample. The order of two items was also changed following feedback. In addition, 10 statements which had more than one-third of participants responding as 'unsure' were reviewed, as were an additional three statements, which one or more respondents missed, to consider whether statement wording might be ambiguous or problematic (Oppenheim, 1992).

Participants offered suggestions via the feedback forms for topic areas that may have warranted inclusion in the scale. These suggestions included: the impact of Advance Statements on carers; the risk of being coerced, or prevented/dissuaded from making an Advance Statement; statements about the process of making an Advance Statement and who should be involved; and the timing of making an Advance Statement (at what age). Although these areas were suggested, they were not used to make changes to the scale. The scale already included a number of statements that considered the impact of Advance Statements on decision making for families (which would include carers within the family) and statements about being pressured into making an Advance Statement. During the initial development of the scale, it was decided that statements about the process of making an Advance Statement would not assist in understanding a person's attitude to Advance Statements.

From the feedback forms there seemed to be a need for more information about Advance Statements. In the focus group, the scale prompted considerable discussion and the group raised a number of questions, highlighting a need for more information and advice about Advance Statements. The Participant Information Sheet was improved by including more information about Advance Statements, in particular their legal status; and the inclusion of a reference for an information booklet produced by Help the Aged (2006) (see Appendix 12).

There was a mixed response on the feedback forms as to whether statements that were personally worded led to a different response to generally worded statements, although slightly more participants indicated that they felt that there was no difference in how they responded. The section for additional comments was used largely to express personal views and experiences, and ask questions about the process of constructing an Advance Statement.

## 5. Phase 2 Method

### 5.1 Participants

Phase 2 of the study involved an independent sample of English speaking people aged 50 years old and over. The sample aimed to be representative of gender and stratified over 10-year age bands: ages 50-59, 60-69, 70-79 and 80 years old and over. However, the actual sample was comprised of: fifty-five, 50-59 year-olds (62% female); forty-nine, 60-69 year-olds (53% female); thirty-six, 70-79 year olds (69% female) and twenty-four, 80+ year-olds (75% female). There was one male and two female participants who did not

report their age, and 14 participants who did not specify their age or gender (see Appendix 13 for demographic information).

The sample was recruited from across the country using two methods: opportunistic sampling, as previously described; and through a number of voluntary and community organisations, including: Birmingham Retirement Council, Alzheimer's Society, Crossroads, the Women's Royal Voluntary Society, the Women's Citizens, the University of the Third Age, and Church groups.

## 5.2 Measures

Phase 2 of the study utilised the revised version of the attitudes to Advance Statements scale (see Appendix 14), and the demographic information sheet, which remained unchanged from the pilot phase, apart from a minor change to page layout (moving the text down the page) and adding 'years old' in the age section to increase the likelihood of participants providing data.

## 5.3 Procedure

To establish reliability, Lounsbury *et al* (2006) recommended a large sample of at least five times the number of respondents as items in the scale. For a scale with 40 items, a sample of 200 participants was therefore required. In order to obtain a sufficient sample, 495 questionnaire packs were sent out, based on a response rate for the pilot study of 40% (received within two weeks).



For Phase 2, a total of 189 responses were received within a period of six weeks, of which 181 were usable for analysis. The eight responses not analysed were excluded because two participants had completed pilot versions (that had been emailed to the organisation as an example), three were completed by participants under the age of 50 years old, two participants only returned demographic information and one participant (male, aged 80+) missed 70% of the scale items.

The results from Phase 2 were subjected to: basic data checks; reliability analysis using Cronbach's alpha coefficient to establish internal consistency and potentially identify items that needed to be removed to increase reliability; and principal components analysis (PCA) to determine component structure, and potentially, items to be removed.

Face and content validity were assessed by two groups: Clinical Psychologists working in Services for Older People who are experienced in the area of end of life issues; and by Phase 1 participants, including participants in the focus group. It was not possible to establish criterion validity, as no other instrument existed to measure attitudes to Advance Statements. It was also not possible to establish construct validity or divergent validity this required extensive use of the scale over an extended period, which was beyond the scope of the current project.

## 6. Phase 2 Results

The data was subjected to a number of basic checks. Frequency counts were used to determine that the raw data was within expected parameters and no problems were identified in this respect. Responses with less than 90% complete data (36 out of 40 items)

were excluded, which led to the removal of one participant who responded to only 31 out of 40 items. Of the remaining 180 participants, 24 responded to 38 or 39 items out of 40 (95% or more complete), and 156 participants had complete data, making the dataset 99.6% complete. Given the high response percentage it was appropriate to use rounded mean (integer) imputation for missing values in all subsequent data analyses.

Items were assessed for discriminatory power using the top 25% and bottom 25% of the scale total scores, as advocated by Clark-Carter (1997). The two groups were then labelled as low scorers (in favour of Advance Statements) and high scorers (against Advance Statements). Visual inspection of histograms with normal distribution curves was used to assess if the data was normally distributed for both groups on each item. As the pattern of responses for both groups were not normally distributed on any of the scale items, Mann-Whitney tests were conducted for each scale item to determine whether the two groups showed significantly different patterns of responding from each other. Three items (Q2, Q5 and Q22; see Table 2) were identified as showing non-significant relationships to group ( $p > 0.01$ , two-tailed). These items were therefore removed from subsequent analyses. A significance level of  $p < 0.01$  was used to reduce the probability of a Type I error, given that multiple tests were undertaken. It was not possible to perform a backward stepwise regression (using ‘group’ as the dependent variable and the items as predictors) due to the insufficient number of participants for the number of variables.

		<b>Subscale</b>
<b>2</b>	A person’s preferences about the type of care and treatments they want to receive may change over time	Validity
<b>5</b>	Most doctors do not use Advance Statements in the way the person intended	Guide treatment
<b>22</b>	Advance Statements do not influence doctors’ decisions about care	Guide treatment

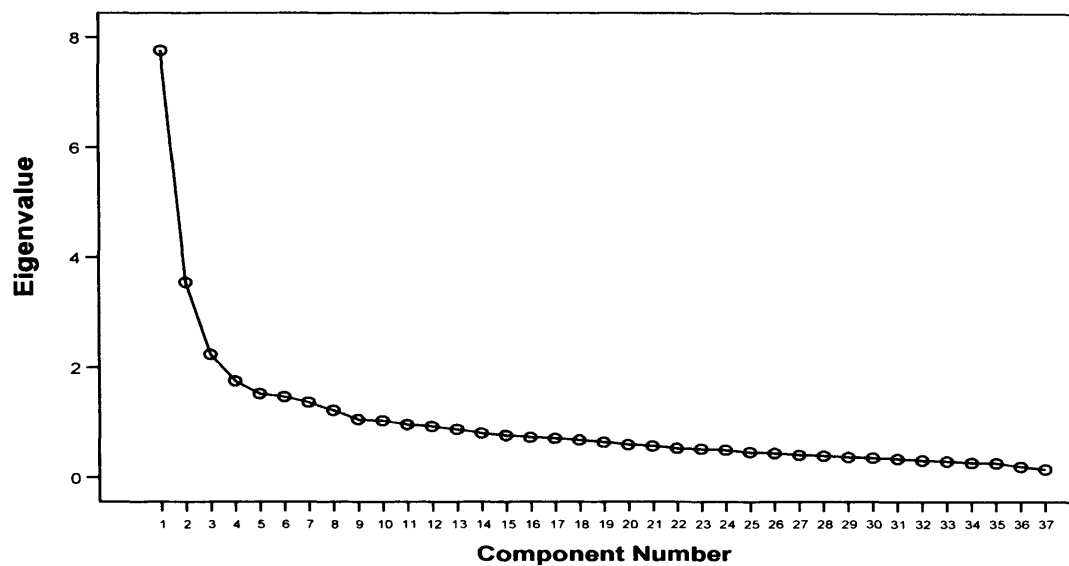
**Table 2:** Items removed based on lack of discriminatory ability

The reliability of the reduced scale (37 items) was assessed using Cronbach's alpha,  $\alpha = 0.861$ , which suggested that the scale had good internal consistency. The 37-item scale was then subjected to principal components analysis (PCA), which was selected as it has been suggested to be psychometrically sound, taking into account all variance (not just shared variance as with factor analysis) and is commonly used in scale development and construction (Field, 2005).

The dataset was initially checked to ensure that it met the criteria for factor analytic procedures. The size of the sample ( $n=180$ ) was very close to the recommended sample size of five times the number of items (Lounsbury *et al*, 2006), which in this case would be 185. The Kaiser Meyer Olkin (KMO; Kaiser, 1970; 1974 cited in Pallant, 2005) value, which is a measure of sampling adequacy, was 0.802, which is regarded as good for factor analysis (Field, 2005). Bartlett's test of sphericity (Bartlett, 1954 cited in Pallant, 2005) was highly significant,  $p < 0.000$ , exceeding the minimum requirement of significance at  $p < 0.05$ , suggesting the data was suitable for factor analytic procedures.

Having established the suitability of the data, PCA was conducted. The initial output suggested that there were 10 components with an eigenvalue  $> 1$  (Kaiser's criterion), accounting for 62% of the total variance (see Appendix 15). The Scree test (Cattell, 1966 cited in Pallant, 2005) suggested retaining three or four components (see Figure 1).

**Figure 1:** Scree plot of eigenvalues



The results of parallel analysis (Horn, 1965 cited in Pallant, 2005) using the Monte Carlo PCA for Parallel Analysis program (Watkins, 2000) suggested retaining four components. In parallel analysis, components are retained if the eigenvalue from the dataset exceeds the average of the eigenvalues obtained from a number of randomly generated datasets (in this case 100) of equivalent size (see Table 3).

Component	% variance	Cumulative % variance	Eigenvalue	Random eigenvalue	Retain
1	20.983	20.983	7.764	1.9747	✓
2	9.589	30.573	3.548	1.8526	✓
3	6.042	36.614	2.235	1.7629	✓
4	4.739	41.354	1.754	1.6764	✓
5	4.114	45.468	1.522	1.6073	✗
6	3.956	49.424	1.464	1.5424	✗
7	3.682	53.106	1.362	1.4818	✗
8	3.290	56.396	1.217	1.4255	✗
9	2.845	59.241	1.053	1.3722	✗
10	2.787	62.028	1.031	1.3176	✗

**Table 3:** Comparison of eigenvalues from Principal Components Analysis and Parallel Analysis

It has been suggested that Kaiser's criteria and Scree testing can lead to an overestimate of the numbers of factors to retain and that parallel analysis has been shown to be the most accurate (Pallant, 2005). However, given that the eigenvalues obtained for Components 3 and 4 were not greatly different from those obtained from random datasets (1.27 times greater and 1.05 times greater respectively), alternative component solutions were considered to see which yielded the clearest and most interpretable component structure.

The dataset was initially re-analysed using PCA specifying a four component solution, given the results of parallel analysis. Both orthogonal (varimax) and oblique (direct oblimin) rotations were conducted to see which yielded the clearest component structure for interpretation. Orthogonal rotation assumes the components to be uncorrelated (independent of each other) and generates components that may be easier to interpret, while oblique rotation assumes that there may be correlation between the components but can be difficult to interpret and report. The aim was to obtain a simple component structure, in which variables loaded strongly on only one component, with each component represented by a number of strongly loading variables (at least above 0.4).

A four component solution, using varimax rotation was obtained (see Appendix 16) that accounted for 41.35% of the variance, as shown in Table 4.

Component	Initial solution			Rotated solution		
	Eigenvalue	% variance	Cumulative variance	Eigenvalue	% variance	Cumulative variance
1	7.764	20.983	20.983	6.213	16.792	16.792
2	3.548	9.589	30.573	3.297	8.912	25.703
3	2.235	6.042	36.614	2.966	8.016	33.720
4	1.754	4.739	41.354	2.825	7.634	41.354

**Table 4:** *Variance accounted for in four component solution following varimax rotation*

Component 1 included 16 items, five of which had moderate loadings on other components (above 0.3). Component 2 included eight items, one of which had moderate loadings on other components. Component 3 included five items, two of which had moderate loadings on other components. Component 4 included seven items, four of which had moderate loadings on other components. One item did not load on any component (Q6; see Table 5). While Components 1 and 2 seemed to represent ‘control/autonomy’ and ‘concerns about validity and risk’, respectively, Components 3 and 4 were more difficult to interpret, potentially representing ‘avoidance’ and the ‘role of doctors’, respectively.

		<b>Subscale</b>
<b>6</b>	It is difficult to talk about death and dying with people close to me	Denial

**Table 5:** *Item not loading on any component in varimax rotation four component solution*

The four factor solution generated using direct oblimin rotation, produced a similar factor structure as the components had no significant correlations (above 0.3) with each other as shown within the component correlation matrix. Therefore it was not necessary to continue to use or report the results of direct oblimin rotation (Pallant, 2005).

Despite parallel analysis suggesting a four component solution, as this led to a number of items loading moderately on more than one component, and two components with only a small number of items with moderate loadings, it was appropriate to consider alternative component solutions (Pallant, 2005).

A five component solution accounted for 46% of the variance. However 16 items loaded above 0.3 on more than one component, and one item did not load on any

components (Q6; see Appendix 17). In addition, Components 3, 4 and 5 were represented by only a small number of items with moderate loadings and interpretation was difficult. A three component solution, which accounted for 36% of the variance, had nine items loading above 0.3 on more than one component and two items not loading on any components (Q6 and Q29; see Appendix 18). Whilst Components 1 and 2 seemed to represent ‘communication to influence care’ and ‘concerns about Advance Statements’, respectively, Component 3 seemed unclear and was difficult to interpret.

A two component solution, which accounted for 31% of the variance, had only three items that loaded above 0.3 on more than one component, and four items that did not load on any components (Q6, Q29, Q36 and Q38; see Table 6 and Appendix 19). The two components seemed easily interpretable as positive attitudes (communication, protection, preparation for the future, autonomy) and negative attitudes (doctors’ privileged role, avoidance, risk, preference for surrogate decision makers, validity) and seemed to map well onto the theoretically derived subscales. Removing the four items that did not load onto either subscale increased the scale alpha slightly from 0.861 to 0.869, and increased the amount of variance accounted for to 33.5%.

		<b>Subscale</b>
6	It is difficult to talk about death and dying with people close to me	Denial
29	Doctors can be trusted to make healthcare decisions when patients cannot choose for themselves	Doctors
36	There is a danger that people will be pressured into making an Advance Statement to prevent them from becoming a burden	Risk
38	Unless a patient expresses their wishes in advance, doctors are likely to do more to keep them alive than many patients would want	Protection

**Table 6:** Item not loading on any component in varimax rotation two component solution

Removing a further five items (Q7, Q13, Q16, Q24, Q34; see Table 7 and Appendix 20) that did not load above 0.4 on either component (Field, 2005), resulted in a scale with 28 items, all of which loaded above 0.4 on one component.

		<b>Subscale</b>
7	Making an Advance Statement could put your life at risk	Risk
13	I would feel alarmed if a healthcare professional tried to talk to me about my future health care needs and preferences	Denial
16	An Advance Statement helps to avoid family disagreements about healthcare decisions for their loved one	Surrogate
24	Advance Statements do not reduce the burden on families for making healthcare decisions	Surrogate
34	Advance Statements cannot totally rule out doubts for doctors and families about care and treatment decisions	Guide treatment

**Table 7:** *Items not loading on any component above 0.4 in varimax rotation two component solution*

Of the remaining 28 items, three items had loadings above 0.3 on both components, with loadings of at least 0.5 on Component 1 and between 0.3 and 0.4 on Component 2 (Q1, Q23 and Q25; see Table 8 and Appendix 21). These items were not removed as this would have decreased the scale alpha to 0.834 and led to a further item loading on both components at above 0.3 (Q37; see Table 8), which if removed would have reduced the scale alpha to 0.826.

		<b>Subscale</b>
1	Having an Advance Statement makes it more likely that your wishes for end of life care would be followed	Guide treatment
23	Making an Advance Statement gives a person a sense of control over the future	Autonomy
25	Advance Statements are a way of talking to doctors and nurses about future illness, care needs and preferences	Communication
37	If I were seriously ill and unable to make decisions for myself, I would expect the doctor to make the decision on my behalf	Doctors

**Table 8:** *Items with loadings above 0.3 on both components in varimax rotation two component solution*



For the 28 item scale, Cronbach's alpha decreased slightly to 0.862 (compared to 0.869 for the 33-item scale), but the amount of variance accounted for increased to 37% (see Table 9). The decision was made to retain 28 items in the scale due to greater internal consistency.

Component	Initial solution			Rotated solution		
	Eigenvalue	% variance	Cumulative variance	Eigenvalue	% variance	Cumulative variance
1	7.159	25.569	25.569	6.613	23.616	23.616
2	3.197	11.418	36.987	3.744	13.370	36.987

**Table 9:** *Variance accounted for in two component (28-item) solution following varimax rotation*

Following the reduction of the scale to 28 items, the split half reliability of the scale was assessed. Although there are numerous ways of splitting the items into two halves, it seemed most logical to divide the scale using the rotated correlation matrix, which was sorted by size (of the correlation coefficient). Items from Component 1 were alternately assigned to each half, as were items from Component 2. This produced two scales of 14 items, with nine items from Component 1 (positive attitudes) and five items from Component 2 (negative attitudes), with approximately equal loadings. The alpha value for Part A of the scale was 0.751, and the alpha for Part B of the scale was 0.750, suggesting the two forms to be equivalent. The correlation between the two forms was 0.802 (uncorrected), which when corrected for using the Spearman Brown prophecy formula to give the equivalent value for a 28-item scale, was 0.890 suggesting that the scale had good reliability.

Given the good internal consistency of the scale and the interpretability of the components, a two component solution for a 28-item scale seemed the most appropriate, despite only accounting for 37% of the variance.

## 7. Discussion

The main aim of the current study was to develop a valid and reliable scale to assess attitudes to Advance Statements. The study resulted in the generation of a 28-item scale (Attitude to Advance Statements Scale; see Appendix 22) with high internal consistency as suggested by Cronbach's Alpha and split-half reliability coefficients, which were 0.862 and 0.890 respectively. The scale items were grounded within the empirical literature on Advance Statements, providing the scale with content validity. The items appeared to both clinicians and people aged over 50 years old to be related to the topic suggesting that the scale also had face validity. It was not possible within the scope of the study to determine criterion validity, as there were no other scales that assess attitudes to Advance Statements, nor was it possible to determine construct or divergent validity as this would require the use of the scale over an extensive period, which was beyond the scope of the present study.

A secondary aim of the current study was to determine how acceptable a scale addressing this topic would be to people aged over 50 years old. This was assessed in a variety of ways including: a feedback sheet given to the Phase 1 sample; a focus group; and consideration of return rates and completion rates. The feedback from participants both on the feedback sheets and in the focus group suggested that the scale was acceptable and understandable, and for a considerable number of people, interesting and thought-provoking. The return rate, which was above 40%, could be regarded as reasonable for a

self-completed, postal return questionnaire indicating acceptability. The good return rate could have been achieved by the assurance of anonymity and the provision of a stamped envelope, which have been suggested to improve response rates (Fink, 2003a; Oppenheim, 1992; Vaux & Briggs, 2006). The very small proportion of missing data (0.5% for 181 participants) also provided some evidence for the acceptability and comprehensibility of the scale items.

Items were constructed based on a qualitative analysis of the literature, to ensure that items were grounded and had content validity. The use of theoretical subscales ensured that the scale included a range and balance of both positive and negative statements. Although scale items were constructed by the Principal Investigator, the wording and meaning of scale items were carefully considered as part of the supervision process. The 40 items included in the Phase 1 scale were selected from a pool of 136 items based on an assessment of the quality of items evaluated against criteria for scale item development (as described in Section 3.4.1) (Bowling, 1997; Fink, 2003b; Goddard III & Villanova, 2006; Oppenheim, 1992) and the meaningfulness of 'strongly agree' and 'strongly disagree' responses. The decisions about which items to include were made by the Principal Investigator in consultation with research supervisors, ensuring the process was as objective as possible.

The scale used in Phase 1 was improved using feedback from participants to alter statement wording to increase clarity. Patterns of unsure or non-response were also used to consider whether statements might benefit from rewording. However, the revised scale, which was used in Phase 2, was not subjected to further pilot testing following the revisions, although this could have been valuable had more time been available for pilot work.

The study involved the use of two independent samples that were recruited through opportunistic sampling and voluntary organisations. This method of sampling had both benefits and drawbacks. The benefits included being able to distribute a large number of scale packs within a relatively short space of time at minimal cost, and to distribute scale packs across the country (including Cheshire, Derbyshire, Leicestershire, Nottinghamshire, Sheffield, and the West Midlands). However, the disadvantages were that the samples largely consisted of white, middle class, Christians (see Appendices 3 and 13), and that certain populations were not approached, such as people who experience social isolation or who do not access the specific voluntary organisations that assisted with this study. In addition, the Phase 2 sample was slightly skewed in terms of the proportions of female respondents and younger respondents (those aged below 70 years old). Given the aim for the sample to be representative of gender, the 50-59 and 60-69 age groups would have ideally comprised 50% female, and the 70-79 and 80+ year old age groups, comprised 56% and 70% respectively (based on 2001 Census data). This skew in the sample may have been a product of sampling or responding. It is highly unlikely that the samples used within this study were truly representative of the population of people aged over 50 years old within the UK, however within the time constraints of the present study, such representativeness would have been very difficult to achieve.

The potential impact of non-representative sampling on the development of the scale needs to be explored. Some studies have found that people who are older, female and know someone with cognitive impairment are more likely to communicate their wishes regarding future healthcare (Bravo *et al*, 2003). However, Nolan *et al* (2005) found that age, gender, race and religion did not predict how patients would choose to have medical decisions made regarding their care. An analysis of the demographic information provided by participants in the present study might help to determine whether attitudes were

influenced by demographic characteristics and might highlight potential issues regarding the adequacy of sampling.

The sample size for Phase 1 ( $n=46$ ) was only slightly lower than desired ( $n=50$ ) and was sufficient to analyse response rates, completion rates, patterns of unsure responses, non-responding and obtain useful feedback to inform the development of the scale for Phase 2. The focus group was of an appropriate and manageable size ( $n=6$ ) and included an equal number of men and women across the age range sampled. The sample size for Phase 2 was only slightly lower than five times the number of items that some authors have recommended (e.g. Lounsbury *et al*, 2006), and the statistical tests of sampling sufficiency suggested that the number of participants was adequate for the statistical procedures used. However, there appears to be no consensus about the sample size required to undertake factor analysis, and others have suggested sample sizes in excess of 300 (Tabachnick & Fidell, 2001). It is possible that a larger sample may have been desirable for the current study.

The response rate for Phase 2 of the study (approximately 40%), while acceptable for a study utilising postal return, means that a significant proportion of the sample approached did not respond. Given the sampling methods and anonymous postal return, it was not possible to identify any of the characteristics of non-responders. It is therefore difficult to determine if certain people chose not to respond on the basis of acceptability of the topic or comprehensibility of the scale; whether certain characteristics or factors made it more or less likely for certain people to respond; or whether some people did not complete it simply because they do not like completing questionnaires of any kind. It is possible that not all of the questionnaire packs distributed were given out to potential participants, which would have resulted in an underestimate of response rate. However, it is not possible to

determine if this occurred and if so how many packs were not given out. Future research could consider response rate and reasons for non-response more closely, and greater effort could be made to encourage completion and return, such as postcard reminders (Bourque & Fielder, 2003).

The possible limitations in sampling and the potential for response bias could have implications for the range of views captured within the current study and the generalisability of the results. The use of non-clinical populations also has implications for the application of the scale with clinical samples, where factors such as poor physical or mental health, specific health problems or conditions, or long-term experiences of services may have an impact on attitudes. Therefore, it will be important to replicate the study with other populations (such as clinical populations of older people, adults with serious, life threatening or life limiting physical health problems, people in the early stages of dementia, or NHS staff) to determine whether the same factor structure and scale items would result.

Although the statistical analysis of the data was thorough, and well established statistical procedures were used for the construction and refinement of the scale, there were some potential methodological limitations of the current study. The ratio of participants to variables when examining the differences between high and low scorers (top and bottom 25% of total scores) limited the use of more sophisticated statistical tests such as backwards step regression. However, given the degree of the non-significant relationships to group (high or low scorers) for the three items removed and the significant relationships to group for the 37 items retained (32 of which were significant at  $p < 0.005$ ), it seems likely that the appropriate items were removed and retained.

Principal component analysis (PCA) was used for scale analysis, as it is advocated for use in scale development (Field, 2005). Despite the potentially limited sample size, the data was assessed as suitable for PCA with a high KMO value and highly significant result on Bartlett's test of sphericity. Although parallel analysis has been suggested to be the most reliable means of determining the number of factors or components to retain, in practice, it is a subjective decision (Pallant, 2005). Therefore the decision was made to reject a four component solution, in favour of a more simple and interpretable two component structure, which incorporated both positive and negative attitudes. A potential limitation of the component structure accepted for the final scale is that it accounted for only 37% of the variance in the scale, suggesting that one or more other factors or variables may have a significant effect on attitude.

The component solution selected led to the exclusion of certain items that did not load on any (either) component. The decision to exclude items with component loadings below 0.4 was based on Field's (2005) recommendation that items should load on factors (components) at 0.4 or above. The decision not to exclude items with loadings on both components was based on the reduction in reliability. However, had those items been removed, the resulting 24-item scale would have comprised two components with all loadings above 0.4 and no items with multiple loadings, with Component 1 (positive attitudes) consisting of 15 items and Component 2 (negative attitudes) consisting of nine items. It is arguable that this solution may have been preferable despite the reduction in alpha, which would still have been above 0.8. An alternative way of excluding items would have been through reliability analysis to increase the value of alpha. This method was not used because the initial alpha value was high and the exclusion of items did not lead to a considerable increase.

It has been suggested that the use of Cronbach's alpha in psychological literature as an index of reliability, although common, is potentially misleading (Shevlin *et al*, 2000). Shevlin *et al* (2000) found that alpha was effected by systematic error and sample size. It is possible therefore that the high estimate of alpha reported in the current study, may indicate the presence of systematic error.

The items comprising the adopted two component solution appeared to fit with most of the themes that emerged from the literature. Although the subscales were not expected to, and did not appear as separate components from principal component analysis, the general split of positive attitudes and negative attitudes emerged as separate components.

Of the items removed, one item from the 'validity' subscale and two items from the 'guide treatment' subscale were found to be non-discriminatory between high and low scorers; three of the items from the negative attitude subscales (denial, doctors' role and risk) and one item from one of the positive attitude subscales (protection) were shown not to load above 0.3 on either component; and five items: one from the 'risk' subscale, one from the 'denial' subscale, two from the 'surrogate' subscale, and one from the 'guide treatment' subscale had loadings below 0.4.

Some of the items removed from 'guiding treatment' and 'protection' subscales made reference to how doctors use Advance Statements, and perhaps reflected participants' views about doctors rather than Advance Statements. Some participants may have had ambivalent feelings about doctors or found it difficult to comment on the extent to which they trust doctors in general, rather than a specific doctor, such as their GP.



In the literature, the role for Advance Statements in guiding treatment seems to be central, along with communicating preferences and ensuring autonomy. However, three of the four ‘guide treatment’ subscale items were removed from the scale and one loaded on both components, which may suggest that the items representing this subscale were not sufficiently related or limited to guiding treatment. Alternatively, it could suggest that people may be fearful or ambivalent about the extent to which they are able to, or would wish to, influence care and treatment decisions.

There is considerable debate within the literature about the role of surrogate decision makers. The potential importance of trust in a chosen surrogate or the availability of an appropriate surrogate may be reasons that two of the four ‘surrogate’ subscale items were removed from the scale. Some participants may have found it difficult to respond to questions about surrogate decision makers on a general rather than personal level due to the relevance of personal circumstances. Others may not have regarded Advance Statements and surrogate decision makers as mutually exclusive options for end of life decision making.

A number of authors have made reference to the potential dangers or risks Advance Statements pose, yet two of the four questions from the ‘risk’ subscale were removed. This may have been due to some of the ‘risks’ not being perceived as risks. In relation to Q36 (Appendix 14): ‘There is a danger that people will be pressured into making an Advance Statement to prevent them from becoming a burden’, one of the participants in the focus group commented that people ‘have the right not to be a burden’. Alternatively, participants might have felt that they did not know enough about Advance Statements and how they could be used, in order to make a judgement.

It has been suggested that people find it difficult to talk about death and dying (Burchardi *et al*, 2005; Laakkonen *et al*, 2004) and that is natural to avoid conversations about death and dying (Callaghan, 2005; Sypher, 2002). It was anticipated that an avoidance of or difficulty with conversations about death and future mortality would be related to a negative attitude towards Advance Statements. However, two of the items from the 'denial' subscale were removed. Item 6: 'It is difficult to talk about death and dying with people close to me', was removed because it loaded on neither of the two components. This may suggest that difficulties in talking to others may not be an avoidance or denial, or related to their attitude towards death and dying or Advance Statements, but may be related to others' reluctance to engage in those conversations or lack of opportunity (Seymour *et al*, 2004). The item related to feeling alarmed if professionals initiated discussions about end of life care and treatment, loaded positively on Component 2 (negative attitudes) but below 0.4, which may suggest the significance of other factors such as trust and the relationship.

Of the remaining subscales, one item was removed from the 'validity' subscale, 'doctors' subscale and 'protection' subscale. The validity item related to the stability of preferences over time, and was non-discriminatory between high scorers (in favour of Advance Statements) and low scorers (against Advance Statements), suggesting that many participants may have considered that their care preferences might change in the future. The item that stated 'doctors can be trusted to make healthcare decisions when patients cannot choose for themselves' did not load onto either subscale. This could be because: participants found it difficult to answer a general question about 'doctors'; participants experienced ambivalent feelings or a range of feelings unrelated to their attitudes towards Advance Statements; or trust and relationships are a separate component influencing attitudes. The item from the 'protection' subscale relating to 'doctors doing more than a

patient would want to keep them alive', was removed because it did not load onto either component. It is possible that the role of doctors within this statement may have affected responding, as previously discussed.

Interestingly, all of the items from the 'communication', 'autonomy' and 'preparation' subscales were included in the final scale, although two items (from the 'autonomy' and 'communication' subscales) loaded on both components, and one of the reversed scored 'preparation' subscale items loaded on Component 2. The three most strongly loading items from Component 1 (positive attitudes) were all items from the 'communication' subscale, suggesting the centrality of communication as a benefit of making Advance Statements (Fagerlin & Schneider, 2004; Sommerville, 1995). This could be viewed as supporting the findings of Seymour *et al* (2004) who found that older people focused on the ways in which Advance Statements could help their families in the event of their incapacitation. Items representing 'autonomy', which is often cited as the main benefit of Advance Statements (Beauchamp & Childress, 2001; Rashid, 2004; RCN, 1994), also loaded positive and quite highly on Component 1, but not as highly as items related to Advance Statements as a form of 'protection', themes which also emerged in the study by Seymour *et al* (2004). The emphasis on protection as a benefit of Advance Statements might reflect issues of trust in doctors, the marginalisation of older people (Seymour *et al*, 2004) or fears of life being sustained by treatment when quality of life becomes drastically diminished (Burchardi *et al*, 2005). Preparation also emerged in the study by Seymour *et al* (2004), with Advance Statements seen by older people as a means of sensitising patients and families to health issues, enabling them to cope better in the future with discussions about treatment and care. The only items within Component 1 from negative subscales were reverse scored items relating to the views expressed in Advance Statements being

more important than the views or wishes of family, and Advance Statements should be legally binding on doctors (Dyer, 1998).

Component 2 (negative attitudes) included items from all of the negative subscales, with one from each in the top five loading items. The strongest loading item was from the 'denial' subscale relating to the pointlessness of thinking about things until they happen. From a psychological perspective, this item would be expected to load highly on Component 2 (negative attitudes), as denial inhibits planning for the future (Rousseau, 2003). The next strongest loading items related to: interfering with doctors freedom to make the best decisions; the risk that a treatment that could aid recovery might be prevented (Ryan, 1996, Sommerville, 1995); that preferences expressed when well are unlikely to remain the same when faced with the prospect of death (Roberts, 2001); and that surrogate decisions makers are preferable when possible (Fagerlin & Schneider, 2004; Sommerville, 1995), all of which have been strongly argued within the literature as reasons for the unfeasibility of Advance Statements. This finding supports the view that some older people expect doctors to make decisions on their behalf (Seymour *et al*, 2004), which may reflect generational differences or power imbalances. It also supports the finding that older people expect their families to assume decision making responsibility if they were to become incapacitated, regarding trusting one's family as ideal (Seymour *et al*, 2004). Three items from 'validity' subscale loaded on Component 2, suggesting that the future applicability of Advance Statements is a concern to older people, in support of the findings of Seymour *et al* (2004). The only item from a positive subscale to load on Component 2 was related to the inability of Advance Statement to prepare people for what might happen in the future. This perhaps suggests that people who have a negative attitude towards Advance Statements might regard the future as unpredictable, and may have an external locus of control.

The generation of a valid and reliable scale that assesses attitudes to Advance Statements has a number of potential clinical applications. The Attitudes to Advance Statements Scale could be used as a tool to facilitate or initiate discussions about end of life issues and care planning with clients who may be experiencing anxiety or emotional distress, where such discussions could be of psychological benefit by increasing perceived control (Affleck *et al*, 1987; Bremer, 1995; Michie *et al*, 2005). The scale could not only be used with older people, but with adults with life-threatening, life-limiting or terminal conditions.

The generation of the Attitudes to Advance Statements Scale, which has been developed using sound methodological and statistical approaches can be viewed as a significant step forward for research focused on attitudes to Advance Statements and end of life care planning. The scale has considerable potential for use in clinically applied research to explore factors that influence attitudes to Advance Statements and consider how attitudes may change over time or over the course of an illness. The scale could be used to evaluate service developments aimed at involving older people in their own care decisions, in line with Standard Two of National Service Framework for Older People (2001), or initiatives to make older people more aware of Advance Statements and Advance Directives, now that Advance Directives have legal status under the Mental Capacity Act (2005). The scale could also be used to assess staff attitudes to their own mortality and care, or adapted to examine staff attitudes about end of life care planning for their clients.

Future research might also consider sampling approaches to obtain more representative samples, and non-response rates, reasons for non-response, and improving response rates to the scale. It would be valuable to replicate the study with other populations, including

clinical samples and NHS staff to examine whether a similar factor structure and scale items would result, and possibly use larger samples to reduce the standard errors of the correlations between items (Kline, 1994). In the study by Seymour *et al* (2004) ‘the need to build trusting relationships with clinicians’ emerged as one of five core categories. It might be valuable for future research to consider how the issues of ‘trust’ and ‘relationships with health professionals’ influence attitudes to Advance Statements.

There is considerable scope for further research to develop the scale, and confirm and establish its psychometric properties including construct and divergent validity, and temporal stability. In addition, structural equation modelling could be used to specify and test confirmatory factor models, which could establish more reliably dimensionality, identification of correlated errors, and tests of tau equivalence needed to make an unambiguous interpretation of alpha (Shevlin *et al*, 2000).

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Part Three:  
Critical Appraisal

## Critical Appraisal

### 1. Origin of the study

The development of a scale was not the first idea that I had for a project, in fact the area of Advance Statements and end of life issues was not the first topic area that I considered. However, given my previous positive experiences in services for older people, I knew that I wanted to undertake research with this client group. I also knew that I wanted a supervisor who had some interest and investment in the research beyond a contract to provide supervision. The area of end of life issues was of particular interest to my clinical supervisor and the decision to research Advance Statements was arrived at through negotiation. There had been some suggestion of researching attitudes towards euthanasia; however this was met with considerable concern by the University who feared the potential for difficulties with obtaining ethical approval.

The research initially aimed to consider whether psychological concepts such as locus of control and coping style might correlate with attitudes towards Advance Statements. However, the fact that there was no existing measure that could be used to assess attitudes to Advance Statements, it seemed a logical first step to create a scale and establish reliability and validity. The process of creating a research proposal and presenting this to peers and tutors, although initially daunting, was actually very helpful in shaping the research, and in legitimising a project that focused exclusively on creating a scale.



## 2. Early stages of research process

Creating a scale was something that initially seemed very appealing, even though the process was always going to be something of a challenge. At the time of entering into the research project, I had little idea of exactly what scale construction and development would entail. I envisaged that scale development was largely a statistical venture with decisions about factor structure and item removal made on the basis of the results of statistical tests. I did not fully appreciate at the outset, the extent to which qualitative approaches and subjective decision making would be required.

In the early stages of the research, it seemed essential to have read all the literature I could find on Advance Statements, Advance Directives and Living Wills to ensure that I had a thorough understanding of the issues and the arguments of both proponents and critics. It seemed impossible to begin creating the scale, until I had this conceptual understanding. This need for thoroughness continued when I began trying to develop statements for scale items. An initial random process of statement writing based on previous reading was abandoned, realising that the lack of a systematic approach would be detrimental to the scale. At no point did I ever regard the creation of the scale as an academic exercise, and always intended that the research should lead to the rigorous development of a scale that would be clinically useful and of value to future research. The need to be comprehensive and balanced in terms of the range of views expressed seemed very important, although it seemed difficult at times to determine how the range of views within the literature could be represented within a moderately short scale, and capture using a Likert response scale, a person's attitude in a meaningful way.

### 3. Recruitment of participants

The recruitment of participants for Phase 1 was surprisingly straightforward. The sample consisted of participants recruited through opportunistic sampling, with the scale distributed by: my supervisor to friends and Clinical Psychology course staff at Leicester University; and my friends and family. In addition, I was given permission to approach participants from a database of older people who were willing to be involved in research, held by the Psychology Department at Birmingham University. Although not a particularly representative sample, Phase 1 benefited from anonymous feedback from university course staff, who were in a particularly good position to comment on the potential flaws of the scale in terms of construction, response format, wording, and the clarity of information and instructions. The distribution of the scale to non-professionals also provided valuable information on the clarity and comprehensibility of the scale, information and instructions to lay people.

The process of recruiting research participants for Phase 2 was initially surprisingly difficult, and began well before sampling for Phase 1. I found that I met with considerable resistance or reservation from some people who expressed concern about the subject topic and how older people might respond to being asked to complete a scale. At times there appeared to be an almost ageist attitude towards older people's participation in research.

I initially attempted to make contact with voluntary organisations by telephone, using telephone numbers obtained from an internet search for voluntary organisations within Birmingham (Birmingham Index of Voluntary Organisations) and organisations that I knew of from my work in Older People's Services. In the initial telephone contacts it was often difficult to get hold of the appropriate staff who had the authority to give me

permission to recruit through their organisation or assist with the recruitment. Without a draft of the scale, it was often difficult to explain the research and exactly what would be entailed in a way that enabled staff to feel confident about agreeing to assist in the recruitment of participants.

Following initial telephone contacts, which generally were unsuccessful in securing any commitment to assist with the recruitment of participants for the research, I emailed a number of organisations using the details obtained from my internet searches. A number of the individuals or organisations contacted did not respond, despite follow up emails. However, some were more positive and expressed potential interest. The need to develop a draft of the scale became more pressing, as managers wanted to see what the scale might look like before making a commitment. Emailing a draft of the scale to others also seemed to be a way to develop interest in the project.

The process of recruiting the assistance of voluntary organisations was actually quite drawn out, extending over a period of a number of months and requiring numerous telephone calls and emails to secure and maintain interest and commitment. There were some managers with whom I never managed to make contact, despite numerous attempts, although the participation of their organisation would have potentially greatly added to the study and the diversity of the sample (e.g. Age Concern). However, as opportunistic sampling (largely thanks to fellow Trainees and course staff on the Leicester Clinical Psychology Doctorate Course) had been so successful in distributing questionnaire packs, the participation of other organisations was not crucial for sampling sufficiency.

During the recruitment of participants for Phase 2, there was one significant disappointment. One of the organisations, who specifically provided services to the

population of interest for this study (people aged over 50 years old), had offered to distribute 100 questionnaire packs. Despite my suggestion to attend activity groups to promote the research and recruit participants, the organisation stated that the group leaders would distribute the questionnaire packs. It was an oversight on my part not to continue to make regular contact and enquiries about how recruitment was progressing once the questionnaire packs had been delivered. With just over a week to my intended deadline, I found that only 45% of the packs they had been given had been distributed and there seemed little intention of trying to distribute the remainder. I collected the questionnaire packs as quickly as possible and they were distributed via fellow trainees to an opportunistic sample. It is not clear what led to such a poor distribution rate at the organisation. It may have been lack of interest in the research by group leaders or their fears or anxieties about how people they approached might respond, such that some people may not have been asked, given insufficient information or asked in a way that discouraged participation. It could have been that the people attending the organisation went there for an enjoyable morning or afternoon and did not want to bother with questionnaires and refused to complete them. It would perhaps have been beneficial to talk to the group of leaders to discuss my research or to have been allowed to approach participants myself. However, both of these suggestions were politely dismissed as being unnecessary, although in hindsight they could have potentially made a significant difference to distribution and response rates, and reduced the likelihood of response bias.

#### 4. Creating the Scale

Creating the initial scale for piloting (Phase 1) was perhaps one of the most time-consuming elements of the research process. Generating good quality scale items that reflected the range of potential views on the topic of Advance Statements, in a way that could be meaningfully scored was a significant challenge. A considerable amount of time was spent gaining an understanding not only of the literature on Advance Statements but also of the principals of scale development. It seemed crucial to get this phase of the research 'right', as it would be the foundation for all subsequent work.

It seemed essential to be systematic in examining the literature to identify discourses and themes, and be as inclusive as possible in generating scale items. It also seemed important not to make the scale too long and overly demanding for participants, particularly given that my sample would include people in their 70's, 80's and perhaps even their 90's. There was also an additional motivation for limiting the scale length, in terms of the implications for participant numbers needed to undertake factor analytic procedures, given the recommendation for a sample size of five times the number of items (Lounsbury et al, 2006).

Once the themes from the literature had been identified, there was a process of narrowing themes to reduce overlap and then broadening sub-themes to ensure comprehensive coverage of the topic. This process at times felt hugely cognitively demanding and it felt absolutely necessary to immerse myself in the data. Once the themes and sub-themes were determined, the process of developing scale items required further reference to the literature to make the scale items as grounded as possible. I particularly wanted to draw on the work of Seymour et al (2004) in generating scale items because they

had conducted focus groups with older people on the topic of Advance Statements, which felt like a precursor to the research I was undertaking.

## 5. Phase 1

I experienced considerable anxiety at the piloting stage, in part due to having to ‘let go’ of the scale, and in part due to an awareness of the limitations of time, having spent such a considerable period gaining an understanding of the literature and research methodology, and developing the scale items.

There was anxiety about how people would respond to the scale, if they responded. I was worried about the feedback that I might receive about the scale, and although open to new ideas and suggestions from participants, was also fearful that I would be inundated with suggestions that might be difficult to incorporate, that would be contradictory or that would require such significant revisions that the scale would need to be re-piloted.

It was however, both exciting and reassuring to receive responses and to find that the majority of participants seemed to find the scale acceptable and understandable; that there were few missed responses, and that people expressed interest in the topic and took time to write about personal experiences or how it had prompted discussion with friends or family. The proportion of responses (40% received within two weeks, 50% within four weeks) felt very promising for the next phase. At the same time, I was aware that given the differences in recruitment, the Phase 2 sample would not necessarily be as interested in the research or as willing to be involved as the sample used in Phase 1. Therefore it seemed appropriate to be conservative about the response rate that might be achieved within a

specific time frame and be prepared to accept that the sample size desired might not be achieved.

Analysis of the data received was comprehensive, although the actual responses to the scale items were irrelevant at this stage. However, what was of interest was when items were missed; when participants indicated that they preferred not to think about an item; and when participants responded as unsure. In addition, the feedback sheets were very carefully analysed to understand how the scale and supporting information might be improved. The analysis of feedback was carefully considered in supervision, and considerable thought was given to: which statements to reword; how they might be reworded; and the potential meaning(s) of the statement and the implications for the meaningfulness of responses in relation to understanding a person's attitude to Advance Statements. The decision not to re-pilot the scale at this stage felt uncomfortable, but necessary given the time available. I had to be satisfied that the collaborative process of statement rewording, taking into account the feedback of Phase 1 participants would be sufficient to enhance the scale and address any problems.

## 6. Phase 2

Distribution of the scale for Phase 2 happened reasonably quickly, although still took longer than I had anticipated or at least hoped. It took approximately two to three weeks to distribute the majority of the questionnaire packs. Although with some packs returned from an organisation having not been distributed, it took four to five weeks to get all of the questionnaire packs out to potential participants. This had an impact on the data collection period, which was extended to six weeks (from four weeks originally planned) to obtain a

number of responses close to that desired. Having already accepted that I might not achieve 200 responses, it felt reasonable to stop data collection at 181 usable responses, particularly given that tests of sampling sufficiency (KMO; Kaiser, 1970; 1974 cited in Pallant, 2005) suggested that the sample was adequate for factor analysis. Despite receiving additional responses after the cut-off point, it felt sensible and appropriate not to include these within the analysis. It might however, be interesting to re-run the analysis with the addition of this data to determine if the same result would have been obtained.

Actually getting data back for the main data collection phase felt incredibly exciting and the initial influx of responses was very uplifting and motivating, and made the task of data entry far less dull than it might otherwise have been. I began experimenting with data analysis when I had over 100 responses, which again felt incredibly exciting and encouraging. Once I had sufficient data (or decided to stop collecting data), I became engrossed in the analysis of the data. I had initially assumed that this would be a quick, clinical process and that the revised, reduced scale would be ready for printing and distribution to a test-retest sample (which would have been Phase 3) within a matter of days. However, this was not the case. I actually spent a great deal of time analysing the data, conducting a variety of statistical tests and working through a number of stages of analysis. It was not always clear from books on the subject of scale analysis, which procedures should be done in which order, with different authors advocating different approaches. It seemed critical to have statistical advice at this stage and my meeting and email communications with the statistician were extremely helpful in confirming the approach and statistical tests that I had utilised for the analysis were appropriate, and advising me of additional considerations of which I had not been aware. Factor analysis (principal components analysis in this case) turned out to be more of an art than a science in terms of determining which factor solution to accept. This felt rather disconcerting,



having expected that a quantitative, statistical approach would lead to clear, procedural decision making. The subjectivity of the decision about component structure and scale items to exclude therefore felt like a responsibility. It seemed that it was important to make the 'right' or at least a well justified and informed decision for what would be the 'final' scale. As it took much longer than anticipated to reach the point where I felt justified in my decision, the possibility of a third phase to establish test-retest reliability seemed unrealistic. The test-retest phase posed a number of potential difficulties in terms of ensuring anonymity, whilst still allowing responses to be matched. I had intended to overcome this difficulty by asking participants to write a nickname, memorable word or number on the top of the first page of the scale. An additional difficulty with test-retest was ensuring an interval of two weeks between administrations/completions. It was possible that leaving both scales with participants might lead to some participants forgetting to complete the second scale or not completing it at the appropriate time. An alternative would have been that identified participants were simply approached again two weeks after they were initially approached, although some participants may not have completed the first scale or may not have completed it immediately. Although a test-retest approach presents practical and logistical issues they are not insurmountable, and I intend to conduct test-retest with a sample of 30 participants or more to explore temporal stability of the scale.

## 7. Research supervision

The experience of supervision was generally a positive one and it was certainly a motivating one. It was very helpful to have deadlines to work to, although I was not always successful in meeting them, often due to my need for thoroughness and

comprehension. Despite this, there was never any expression of disappointment, although at times I sensed a degree of alarm or concern about my meticulous approach and the consequences in terms of time; a feeling I myself tried to suppress with my firm belief that everything would be alright and that it would get done.

Supervision helped me to not feel alone in the research process; knowing that two other people (at the very least) cared about the project and how I was doing, and were prepared to give up their time and energy to help think things through. It was invaluable to have people that I could check the quality of my work with prior to printing and distribution. Unlike a qualitative project that can be developed through an iterative process, the creation of the scale at each stage felt very final and details such as question wording and format were therefore very important.

Having support from a statistician was also particularly valuable, in terms of confirming that the approach to data analysis I had taken was appropriate and prompting further considerations. It was helpful to have someone to provide reassurance and to ask questions, although I was ultimately responsible for decisions about which approach to use, which items to remove and which component solution to adopt.

## 8. Summary of Reflections

### 8.1 Time

The concept of time is one that has been central in this study and in my reflections on it. Throughout the research, I seem to have often underestimated how long things would

take or how much I could do within the time available. This difficulty was not helped by personal circumstances that I had not anticipated and that were highly draining on my time. In addition, my need for thoroughness and understanding, and the desire for it to be 'right' were also problematic for my progression through the stages of the research. However, while this approach has delayed some aspects of the research, I feel that it helped me to gain a good understanding of research methodology and statistical approaches. It also gave me a sense of confidence that my approach and decisions were justifiable and defensible.

I was extremely disappointed that the study became a two phase design, rather than three phase design, having had every intention from the outset of examining the temporal stability of the scale using a test-retest approach. However, I had to accept my limitations and the limitations of time.

## 8.2 What I Learned

Having not previously undertaken a project of this magnitude before, I have learned a great deal from it. It was helpful to complete a research project at this level in its entirety, having only previously engaged in aspects of research projects or small scale research (single case design and service evaluation). The process of developing ideas and determining what it is realistic to achieve within a given amount of time and with limited resources, was one that was particularly valuable and which was an ongoing process throughout the research.

I was surprised to find how interested I became in the research topic, the extent to which I engaged with the literature and the data, and how this interest was sustained throughout the research. I am sure this was helped by the feedback, interest and enthusiasm of others, and some of the conversations that arose as a result of the research.

I learned about the difficulties and importance of engaging others in the research process and the need to sustain their interest and motivation. In this case it was voluntary organisations but in future research could be NHS Trusts, managers or professional groups. More direct involvement with the organisations during this research might have been beneficial. The amount of time needed for the distribution of questionnaire packs was underestimated, which subsequently effected the period allowed for data collection and in future research I will bear this in mind.

I felt that undertaking the study was an excellent way of learning about research methodology, providing both a motivation and context for learning. There was nothing that I undertook or carried out that I did not first seek to understand the reason for doing, the alternatives and the best course of action. Given this, I felt able to explain and justify every course of action and every decision.

Having supportive supervisors made a huge difference in terms of my motivation and confidence. Regular meetings and interim email communications made the process feel more collaborative and provided an opportunity for me to articulate my thinking and feel reassured.

### 8.3 Attitude to Future Research

I have heard many people say that ‘by the end of your research, you will be sick of it’, but I don’t feel that way at all about it, in fact I feel quite the opposite. Although it has been hard work and time consuming, I have actually really enjoyed undertaking the study, even though the topic was not one I had a deep-rooted passion for at the outset. I think that some of this enthusiasm for the research has come from doing something new; from creating something; the interest other people have expressed in what I have been doing; and the relevance to current developments in policy (e.g. Mental Capacity Act, 2005) and current social and media interest.

Although I have not had time to undertake an investigation of temporal stability, I intend to undertake a test-retest approach and publish the scale. I would also like to undertake an analysis of patterns of responding in relation to demographic data collected. Although I am aware that there are potential methodological issues in using data collected from the full 40-item scale, given the potential influence of other scale items on responses, it would provide a basis for further investigation with the reduced 28-item scale.

Having completed this study, I feel much more confident to engage in further research and look forward to the benefits and challenges of working as part of a research team rather than an individual researcher (with supervision).

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Seymour, J., Gott, M., Bellamy, G., Ahmedzai, S.H. & Clark, D. (2004). Planning for the end of life: the views of older people about advance care statements. *Social Science and Medicine*, **59** (1), 57-68.

## Appendix 1

### Notes for Contributors to British Journal of Health Psychology



The  
British  
Psychological  
Society

**You Are Here:** Home > Publications > Journals > British Journal of Health Psychology  
> Notes for Contributors

# Notes for Contributors

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

## 1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

## 2. Length

Papers should normally be no more than 5000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

## 3. Editorial policy and reviewing



The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)



The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to the title page (and the text should be free of such clues as identifiable self-citations e.g. 'In our earlier work...').

## 4. Online submission process

- 1) All manuscripts must be submitted online at <http://bjhp.edmgr.com>.  
**First-time users:** Click the REGISTER button from the menu and enter in your details as instructed. On successful registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if your status changes e.g. author, reviewer or editor).  
**Registered users:** Click the LOGIN button from the menu and enter your user name and password for immediate access. Click 'Author Login'.
  - 2) Follow the step-by-step instructions to submit your manuscript.
  - 3) The submission must include the following as separate files:
    - o Title page consisting of manuscript title, authors' full names and affiliations, name and address for corresponding author - 
    - o Manuscript title page template
    - o Abstract
    - o Full manuscript omitting authors' names and affiliations. Figures and tables can be attached separately if necessary.
  - 4) If you require further help in submitting your manuscript, please consult the Tutorial for Authors - 
- Editorial Manager - Tutorial for Authors

Authors can log on at any time to check the status of the manuscript.

## 5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions -



British Journal of Health Psychology - Structured Abstracts Information

- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association, Washington DC, USA (<http://www.apastyle.org>).

## 6. Publication ethics

Code of Conduct -



Code of Conduct, Ethical Principles and Guidelines

Principles of Publishing -



Principles of Publishing

## 7. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

## 8. Post acceptance

PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication for easy and cost-effective dissemination to colleagues.

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## 10. Checklist of requirements

- Abstract (100-200 words)
- Title page (include title, authors' names, affiliations, full contact details)
- Full article text (double-spaced with numbered pages and anonymised)

- References (APA style). Authors are responsible for bibliographic accuracy and must check every reference in the manuscript and proofread again in the page proofs.
- Tables, figures, captions placed at the end of the article or attached as separate files.

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## **Appendix 2**

### **Confirmation of NHS and University Research Registration**

Research & Development Office  
Daisy Peake Building  
Gipsy Lane  
Leicester  
LE5 0TD  
Tel: 0116 225 3743  
david.clarke@leicspart.nhs.uk

Miss Daniella Wickett  
198 Kings Road  
Kingstanding  
Birmingham  
B44 0SS

25<sup>th</sup> January 2007

Dear Daniella

**The Development of a Scale to assess attitudes to Advanced Statements  
(PI: Daniella Wickett) Ref: ELMH0464**

Thank you for applying for NHS Permission to Conduct Research for the above-named project. This study has now been validated and reviewed according to the Standard Operating Procedure for research appraisal. The study therefore has been granted the following level of approval:

Full Approval	<input checked="" type="checkbox"/>	Approval in Principle	<input type="checkbox"/>	Approval refused	<input type="checkbox"/>
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Under the research governance policy of the Trust, confirmation of appropriate ethical approval is a necessary prerequisite for Trust Approval. I can confirm that this study falls outside the remit of the COREC system (healthy volunteer study not on NHS premises). Leicestershire Partnership NHS Trust (LPT) provides indemnity for this study, and Sponsorship of the study have been confirmed as the joint responsibility of LPT and the University of Leicester.

Trust Research Approval is conditional upon:

- Adherence to the agreed protocol
- Presentation of final report/summary findings to the Trust/Participants at the conclusion of the study.
- Any changes in the protocol, timescale etc. are notified to the research office.
- A copy of any subsequent publication is lodged with the Trust.

With best wishes on the success of your study.

Yours sincerely




Dr. Dave Clarke  
(Associate Director, R&D)

# **SPECIAL NOTE**

**THE FOLLOWING**  
**IMAGE IS OF POOR**  
**QUALITY DUE TO THE**  
**ORIGINAL DOCUMENT.**

**THE BEST AVAILABLE**  
**IMAGE HAS BEEN**  
**ACHIEVED.**

 You replied on 23/06/2007 15:14.

**Wickett, D.M.**

**From:** Colman, Prof A.M. [amc@leicester.ac.uk]  
**To:** dmw20@leicester.ac.uk  
**Cc:**  
**Subject:** RE: PC\_ethics2006 - Daniella Wickett  
**Attachments:**

**Sent:** Thu 18/01/2007 17:38

Dear Daniella

Your project (The Development of a Scale to Assess Attitudes to Advance Statements) has been approved by the Psychology Research Ethics Committee.

This e-mail is the official document of ethical approval and should be printed out and kept for your records or attached to the research report if required - this includes all undergraduate and postgraduate research.

We wish you every success with your study.

Andrew M. Colman  
Psychology Research Ethics Committee Chair

-----Original Message-----

**From:** Web Server Account [mailto:websrvr@www.le.ac.uk]  
**Sent:** 18 January 2007 11:44  
**To:** amc@leicester.ac.uk  
**Subject:** PC\_ethics2006 - Daniella Wickett

**Proposer:** PC\_ethics2006 - Daniella Wickett  
**email:** dmw20@le.ac.uk  
**status:** 3rd year clinical psychology doctorate course  
**supervisor:** Dr Marilyn Christie  
**title:** The Development of a Scale to Assess Attitudes to Advance Statements  
**date:** 17/01/2007  
**preapproval:** none  
**describe:** Y  
**tellvoluntary:** Y  
**obtainwrittenconsent:** na  
**observe:** na  
**maywithdraw:** na  
**allowomit:** Y  
**tellconfidential:** Y  
**debrief:** na

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**mislead:** N  
**distress:** Y  
**animals:** N  
**kids:** N  
**sen:** N  
**patients:** N  
**custody:** N  
**criminals:** N

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**route:** B

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 routeAdesc:

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 routeBdesc: AIM: The aim of the proposed study is to develop a valid and reliable scale that will assess an individual's attitudes towards advance directives in healthcare. RATIONALE: Although there has been considerable debate within the literature about the use of advance statements, it appears there has been little consideration of the views and attitudes of older people, particularly within the UK. However, public interest in the area of advance statements is growing and advance statements are on the Government's agenda for older people (DOH, 2001b) and the National Service Framework for Older People (DOH, 2001a) promotes person-centred care, patient choice and autonomy as service standards (Standard 2). In addition the Mental Capacity Act (2005), explicitly states a role for the use of 'advance directives' to refuse treatment (section 24), considers the validity and applicability of advance decisions (section 25) and the effects of advance decisions (section 26). Research conducted by Seymour et al (2004) has provided a qualitative exploration of older people's attitudes, however further work is required to enable this information to be utilised within a clinical setting. There is currently no existing measure to examine attitudes to advance statements, which limits any research that can be done in this area. Creating a valid and reliable scale to assess attitudes to advance statements is an essential next step for research in the area of advance statements and end of life care planning. Once developed, the scale could be used in further research focusing on attitudes towards advance statements in relation to specific conditions or circumstances, or to consider factors that may be related to or influence attitudes to advance statements. It could also be used with service users within NHS health and mental health services to promote autonomy and involvement in healthcare decision-making and open a dialogue about end of life care planning and decision making. Further work could be

done to

establish the validity and reliability of the scale with a younger sample, which would enable it to be used with NHS staff working with older people or in services for clients with terminal illnesses or life-limiting conditions, or with younger clients themselves. METHODS & MEASUREMENTS: The study will involve the development of a scale to assess attitudes towards advance statements. The scale items will be generated based on the research literature including a qualitative study conducted with older people examining views to advance statements (Seymour et al, 2004). The scale will include a balance of positive and negative views towards advance statements and will include a five worded response options from strongly agree to strongly disagree. Participants will also be given a response option to state that they do not wish to think about/answer a particular question at this time. The scale will initially be piloted with approximately 50 older people, following which the views of respondents expressed on the scale and in a focus group will be used to enhance the scale to ensure comprehensibility, acceptability, readability, response format, the sufficiency of information provided and the administration protocol and procedure. On the pilot version of the scale there will be four to six additional questions at the end of the scale (including an open-ended question to allow free-response) to prompt participants to comment on the scale, their experiences of and feelings about completing it and any difficulties they encountered. The revised scale will then be given to



a sample of approximately 200 older people, the results of which will be factor analysed and items removed to increase reliability. The final scale will then be given to a further 50 participants. The scale will also be evaluated in relation to test-retest reliability with a sample of approximately 30 older people. Participants will be given a written information sheet, the scale (in development) and a demographics information sheet.

Participants attending focus groups and those providing retest data will complete a written consent form as their data will not be anonymous to the researcher, but for other participants the anonymous return of their questionnaires is taken as their consent to participate.

**PARTICIPANTS:** The study will involve a community sample of older people (aged 50 years old and over). All samples will require English speaking people aged 50 years and over. The samples will be representative of gender and stratified over 10-year age bands: ages 50-59, 60-69, 70-79 and 80 years old and over. Given that the samples identified could potentially include any English speaking person over the age of 50 years, there may be wide variations in the education level, social and cultural experiences, and the physical and mental health of the participants. Opportunistic sampling and approaching voluntary and community organisations may be the most efficient way of ensuring diversity in the sample and representation of range of views.

**POTENTIAL DISTRESS:** The topic of end of life care has the potential to be distressing to some participants, however as the study relies on volunteers it is likely that those most anxious about death or dying would choose not to complete the scale. Although the topic area may be regarded as sensitive, the scale will ask general questions related to individuals' attitudes to advance statements and the role of family, healthcare professionals and other factors in end of life decision-making. The acceptability of the scale will be addressed as part of the aims of the study, and the scale modified if necessary in light of views expressed by participants. Within the information provided to participants will be guidance about how they can seek information and advice should the research participants experience distress as a result of completing the scale. Participants will be advised to speak to Age Concern for help or advice about creating an advance statement or to their General Practitioner about health care concerns. A reference for a book about advance directives published by Age Concern will also be included within the information.

**CONSENT:** As the majority of participants will be recruited through voluntary and community organisations involved with older people, rather than directly by the researcher, all relevant information pertaining to the study will be included within a questionnaire pack. This pack will include a statement about consent; although it will not include a formal written consent form, as the completion and return of the scale represents implicit consent. It will be made clear to the participant that completing the scale is entirely voluntary and that returning the scale to the researcher will be regarded as consent for their data to be used within the study.

Written consent will be sought from participants completing the scale for establishing test-retest reliability, and from those participating in the focus group, as they (and their data) will be identifiable to the researcher. Any potential identifiable participant should be given as much time as they need to consider their involvement, prior to agreeing to participate. No pressure will be placed on any identifiable individual to participate and they reserve the right to withdraw (or withdraw their data) from the study at any time.

**DEBRIEFING:** As most

participants will not complete questionnaires in the presence of the researcher and that the majority of participants will be anonymous to the researcher, debriefing will not be possible. However participants will be guided to sources of support within the information pack, should they have questions, concerns or experience distress. Information about the results of the study will be distributed to voluntary and community organisations from which participants were recruited, should the results of the study be of interest to them.

RouteBsupp: ETHICAL CONSIDERATIONS: The sensitive nature of the topic (as stated above), which should be in part be addressed by respondent self-selection (those who are particularly death anxious are very unlikely to complete the scale) and through appropriate direction to voluntary organisations and primary healthcare practitioners for information, support or advice. Participants will also be given the option not respond to questions if they do not wish to answer them at this time. Confidentiality and any limits to this will be explained to participants who have been identified for establishing test-retest reliability and for the focus group prior to their involvement in the study (and included within the information sheet). Any data obtained that is not anonymous, will be anonymised by the researcher using a numerical coding system and no identifying details will be included within the research report or any subsequent publication of the research findings. Focus group transcription data will also be anonymised and the tape recording kept in a locked drawer at the School of Psychology, University of Leicester. During the period of the research the raw data (in paper form) will be stored in a locked drawer at the researcher's home. The computerised data will be password protected and a back-up stored on a portable storage device that is also kept in a locked drawer. Following the study, the data (in paper and electronic form) will be securely stored for a period of five years at the School of psychology, University of Leicester, 104 Regent Road, Leicester, after which time the original data will be destroyed. ESTIMATED START DATE & DURATION: The scale is currently under construction and the researcher hopes to approach the pilot sample in February 2007. The project needs to be completed by the end of June 2007.

## **Appendix 3**

### **Summary of Demographic Data for Phase 1 Sample**

### Phase 1 Sample Characteristics

		Age 50-59	Age 60-69	Age 70-79	Age 80+	Unknown	Total
<b>Gender</b>	Male	6	4	7	-	2	19
	Female	5	13	6	-	1	25
	Missing	-	-	-	-	2	2
<b>Marital Status</b>	Single	3	1	1	-	-	5
	Married	5	5	10	-	4	24
	Remarried	-	2	-	-	-	2
	Separated	-	-	-	-	-	-
	Divorced	3	4	-	-	-	7
	Widowed	-	5	2	-	1	8
<b>Ethnicity</b>	White British	11	17	12	-	5	45
	Asian	-	-	-	-	-	0
	Black	-	-	-	-	-	0
	Chinese	-	-	-	-	-	0
	Mixed – White and Asian	-	-	-	-	-	0
	Mixed – White and Black	-	-	-	-	-	0
	Other mixed background	-	-	-	-	-	0
	Any other ethnic background	-	-	-	-	-	0
	Missing	-	-	1	-	-	1
<b>Religion</b>	Christian	10	13	11	-	2	36
	Buddhist	-	-	-	-	-	0
	Jewish	-	-	-	-	-	0
	Hindu	-	-	-	-	-	0
	Muslim	-	-	-	-	-	0
	Sikh	-	-	-	-	-	0
	Other	-	-	-	-	2	2
	None	1	4	2	-	1	8
<b>Education</b>	School – no qualifications	1	3	4	-	2	10
	School qualifications	3	6	-	-	-	9
	College or FE qualifications	4	3	3	-	1	11
	University qualifications	2	3	5	-	-	10
	Work based training/qualifications	1	2	1	-	1	5
	Missing	-	-	-	-	1	1

		Age 50-59	Age 60-69	Age 70-79	Age 80+	Unknown	Total
<b>Highest Occupation</b>	Professional	4	2	5	-	2	13
	Managerial or technical	3	3	3	-	1	10
	Non-manual skilled	3	4	-	-	1	8
	Manual skilled	-	1	1	-	-	2
	Partly skilled	-	4	3	-	-	7
	Unskilled	1	1	-	-	-	2
	Homemaker	-	2	1	-	-	3
	Missing	-	-	-	-	1	1
<b>Subjective health</b>	Very good	1	9	5	-	3	18
	Good	9	8	8	-	1	26
	Poor	1	-	-	-	1	2
	Very poor	-	-	-	-	-	0
<b>Subjective mood</b>	Not at all unhappy	1	7	9	-	4	21
	Unhappy some of the time	9	10	4	-	1	24
	Unhappy most of the time	1	-	-	-	-	1
	Unhappy all of the time	-	-	-	-	-	0
<b>Caring</b>	Previously carer	3	8	5	-	2	18
	Currently carer	-	3	2	-	1	6
	Involved in decision making	6	8	6	-	1	21
<b>Cognitive impairment</b>	Know someone with cognitive impairment	-	1	2	-	-	3
<b>Knowledge of Advance Statements</b>	No previous knowledge or awareness	3	9	4	-	4	20
	Some awareness but limited knowledge	5	5	9	-	-	19
	Moderate knowledge	2	1	-	-	1	4
	Missing	1	2	-	-	-	3
<b>Made an Advance Statement</b>	Thought about making one	1	3	1	-	1	6
	Discussed making one	-	1	-	-	-	1
	Have made one	-	-	-	-	-	0

## Appendix 4

### Consent Form for Focus Group Participants

# Attitudes to Advance Statements

## Participant Consent Form

I agree to take part in the focus group run by Daniella Wickett, Trainee Clinical Psychologist. I understand that the focus group is part of the study to develop a scale to assess attitudes to Advance Statements, which is described in the Participant Information Sheet.

I am aware that the discussions in the focus group will be used to improve the Attitudes to Advance Statements questionnaire before it is given to a large sample of people aged over 50 years old. I am aware that my comments may be included within the study but that I will not be identified.

I agree to allow the focus group to be audio recorded to enable Daniella Wickett to listen to the discussion again.

I have been given the opportunity to discuss details of the focus group with Daniella Wickett and ask any questions. The nature and purpose of the research study and focus group have been explained to me and I understand what will be required if I take part in the study.

I am aware that I can withdraw from the focus group at any time without explanation should I wish to. I understand that even if I choose to withdraw I will still receive my travel expenses and 'thank you' gift voucher.

Signature of participant:

Date:

Name (in block capitals):

I confirm that I have provided participants with information relating the study and have explained the nature of the research and the focus group. In my judgement, the participant has understood the information and is able to give informed consent to participate.

Signature of investigator:

Date:

Name (in block capitals):      DANIELLA WICKETT

## Appendix 5

### Attitudes to Advance Statements Scale – Phase 1 Version



# Attitudes to Advance Statements Scale

## Advance Statements

An Advance Statement is a record of a person's preferences for future medical care and treatment. Advance Statements are designed to be used when a person is no longer able to make a decision or express their wishes about their care. Advance Statements often include a person's wishes about end of life care and the types of treatments they would or would not want to receive. Advance Statements can also be used to outline views and preferences about other things that are important to the person in everyday life.

## Instructions

Please read the questions on the following pages carefully, then circle or tick the response option on the right that best expresses your view (as shown below). If you change your mind about your answer, simply cross it out and circle or tick the response that you feel best expresses your view. Please answer ALL questions as honestly as possible. If you find any question too difficult to think about simply circle option 'I prefer not to think about this'.

## Examples

1	Advance Statements can help to guide doctors in making healthcare decisions	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
1	Advance Statements can help to guide doctors in making healthcare decisions	Strongly agree	Agree	Not sure	<del>Disagree</del>	Strongly disagree	I prefer not to think about this
1	Advance Statements can help to guide doctors in making healthcare decisions	<del>Strongly agree</del>	<del>Agree</del>	Not sure	Disagree	Strongly disagree	I prefer not to think about this

## Attitudes to Advance Statements Scale

<b>1</b>	<b>Advance Statements cannot enhance a person's choice and autonomy</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>2</b>	<b>A person's preferences about the care they would want to receive may change over time</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>3</b>	<b>The preferences a person expresses in an Advance Statement should be more important than the views and wishes of their family</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>4</b>	<b>Advance Statements should be legally binding on doctors</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>5</b>	<b>Doctors are unlikely to use Advance Statements in the way the person intended</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>6</b>	<b>It is difficult to talk about death and dying with people close to me</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>7</b>	<b>Making an Advance Statement could put your life at risk as it could be used incorrectly</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>8</b>	<b>The preferences a person expresses in an Advance Statement should be more important than the opinions of doctors</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>9</b>	<b>Making an Advance Statement encourages a person to think about what is important in life</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>10</b>	<b>A person's preferences about the care they would want to receive may change in the face of serious illness</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>11</b>	<b>Advance Statements can protect dying people from families who do not care</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>12</b>	<b>Having an Advance Statement makes it more likely that your wishes for end of life care would be followed</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>13</b>	<b>I would feel alarmed if a healthcare professional tried to talk to me about my future health care needs and preferences</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>

<b>14</b>	<b>Planning for end of life care with an Advance Statement is just as important as making a will</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>15</b>	<b>An Advance Statement could be misused to deny care for treatable conditions</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>16</b>	<b>An Advance Statement helps to avoid family disagreements about healthcare decisions for their loved one</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>17</b>	<b>Advance Statements interfere with doctors' freedom to make the best decisions about a person's care</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>18</b>	<b>Advance Statements can help families to understand what their relative would want to happen in relation to end of life decisions</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>19</b>	<b>Discussing Advance Statements cannot help to prepare people for what might happen in the future</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>20</b>	<b>Advance Statements can help to protect people against families who may make care decisions for their own interests or gain</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>21</b>	<b>It is important for people to talk about what they would want to happen at the end of their life</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>22</b>	<b>Doctors will act in the way they think best rather than use Advance Statements</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>23</b>	<b>Making an Advance Statement gives a person a sense of control over the future</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>24</b>	<b>Advance Statements do not reduce the burden on families for making healthcare decisions</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>25</b>	<b>Advance Statements are a way of talking to doctors and nurses about future illness, care needs and preferences</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>26</b>	<b>There is no point in thinking about what might happen until something happens</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>
<b>27</b>	<b>By making an Advance Statement you could protect yourself from procedures you are absolutely sure you would never want</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>I prefer not to think about this</b>

<b>28</b>	What you actually want when faced with the prospect of death may not be what you thought you would want	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
<b>29</b>	Doctors should be trusted to make healthcare decisions when patients cannot choose for themselves	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
<b>30</b>	Making an Advance Statement could be risky because it could stop a treatment that could help a person recover	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
<b>31</b>	Writing an Advance Statement would be a good way to tell people what I want at the end of my life	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
<b>32</b>	Advance Statements cannot ensure that people are able to make decisions for themselves at the end of their lives	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
<b>33</b>	It is not possible to make an Advance Statement, as you cannot know what treatments may be available in the future	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
<b>34</b>	Advance Statements cannot rule out doubts about what should be done	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
<b>35</b>	Making an Advance Statement helps to reduce the stress of decision making at a time when a person is seriously ill or dying	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
<b>36</b>	There is a risk that people might make an Advance Statement to refuse treatment because of fears of being a burden to others	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
<b>37</b>	If I were seriously ill and unable to make decisions for myself, I would expect the doctor to make the decision on my behalf	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
<b>38</b>	Unless a patient expresses their wishes in advance, doctors are likely to do more to keep them alive than many patients would want	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
<b>39</b>	Developing an Advance Statement provides an opportunity for patients, doctors and families to talk about end of life decisions	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this
<b>40</b>	Having someone you trust to make decisions on your behalf is better than making an Advance Statement	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	I prefer not to think about this

**Thank you for completing this questionnaire.  
Please ensure that you have answered all of the questions.**

## Appendix 6

### Information About You (Demographics Sheet)

# Information About You

**Age:**

**Gender:**

☐ Male

☐ Female

**Marital Status:**

- ☐ Single (never married)
- ☐ Married (first marriage)
- ☐ Re-married
- ☐ Separated
- ☐ Divorced
- ☐ Widowed

**Ethnicity:**

- ☐ White British
- ☐ Asian
- ☐ Black
- ☐ Chinese
- ☐ Mixed - White and Asian
- ☐ Mixed - White and Black
- ☐ Other mixed background
- ☐ Any other ethnic background

**Religion:**

- |   |                                 |
|---|---------------------------------|
| <input type="checkbox"/> Christian      | <input type="checkbox"/> Hindu  |
| <input type="checkbox"/> Buddhist       | <input type="checkbox"/> Muslim |
| <input type="checkbox"/> Jewish         | <input type="checkbox"/> Sikh   |
| <input type="checkbox"/> Other religion | <input type="checkbox"/> None   |

**How important are religious or spiritual beliefs to you?**

- ☐ Very important
- ☐ Quite important
- ☐ Not very important
- ☐ Not at all important

**Children:**

- ☐ I have children
- ☐ I do not have children

**I have a close relationship with one or more of my children:**

- ☐ Yes
- ☐ No
- ☐ Not applicable

**Education:**

- ☐ School education, no qualifications
- ☐ School education, obtained qualifications
- ☐ Further education / college qualifications
- ☐ University qualifications
- ☐ Work-based training/qualifications

**Highest Occupation:**

- ☐ Professional occupation
- ☐ Managerial or technical occupation
- ☐ Non-manual skilled occupation
- ☐ Manual skilled occupation
- ☐ Partly skilled occupation
- ☐ Unskilled occupation
- ☐ Home-maker

**In general I would describe my health as:**

- ☐ Very good
- ☐ Good
- ☐ Poor
- ☐ Very Poor

**I currently have one or more health problems that:**

Often cause significant levels of pain or discomfort ☐ Yes ☐ No

Often significantly limit my ability to do day-to-day activities ☐ Yes ☐ No

Often require medical treatment or hospital visits ☐ Yes ☐ No

Could be life-limiting ☐ Yes ☐ No

**In the past two weeks, how often have you felt sad or unhappy:**

- ☐ Not at all
- ☐ Some of the time
- ☐ Much of the time
- ☐ All of the time

**Have you ever been a carer for anyone who was very seriously ill or dying?**

☐ Yes      ☐ No

**Are you currently caring for anyone with serious health problems?**

☐ Yes      ☐ No

**Have you ever been involved in making decisions on behalf of someone who was very seriously ill or dying?**

☐ Yes      ☐ No

**Does anyone close to you have a diagnosis of cognitive impairment (e.g. dementia, Alzheimer's disease)?**

☐ Yes      ☐ No

**Awareness of Advance Statements (tick all that apply):**

- ☐ I have not heard of Advance Statements before today
- ☐ I have heard of Advance Statements but do not know much about them
- ☐ I know quite a lot about Advance Statements
- ☐ I know someone who has written an Advance Statement, Living Will or Advance Directive
- ☐ I have thought about making an Advance Statement, Living Will or Advance Directive
- ☐ I have discussed making an Advance Statement, Living Will or Advance Directive with my family or my doctor
- ☐ I have made an Advance Statement, Living Will or Advance Directive

**Thank You**

**Please return this form with your completed questionnaire**

## Appendix 7

### Participant Information Sheet



## **Participant Information Sheet**

### **The Development of a Scale to Assess Attitudes to Advance Statements**

I would like to invite you to take part in a research study. Before you decide whether you would like to take part, please read the following information carefully. This information will explain the study to you, why you have been selected and what taking part in the study would involve for you. You are not obliged in any way to take part in this study, but if you choose to do so your participation would be greatly appreciated. Thank you.

#### **What is the purpose of the study?**

The purpose of this study is to develop a scale that will assess attitudes towards Advance Statements. The study focuses on the views of people aged 50 years old or more, as issues relating to end of life care may become increasingly important to people, for themselves or their family, as they get older. Although there has been research in this area, the views of older people have often been overlooked.

For many people death and dying is difficult to think or talk about, and for some people there are few opportunities to discuss their concerns or preferences. It is hoped that once developed, this scale could be used to help doctors and other health care professionals to understand the needs and wishes of their patients and encourage more discussion about end of life issues and care.

#### **What is an advance statement?**

An Advance Statement is a record of a person's preferences for future medical care and treatment. Advance Statements are designed to be used when a person is no longer able to make a decision or express their wishes due to mental or physical problems (such as confusion or unconsciousness). They are sometimes referred to as Living Wills.

Advance Statements often include a person's wishes about end of life care (for example, resuscitation). Advance Statements can also be used to outline views and preferences about other things that are important in everyday life. An Advance Statement may contain requests for treatment to be stopped in certain circumstances. This is known as an Advance Directive.

An Advance Statement cannot instruct a doctor to deny basic care (which includes food, water and hygiene); act against their clinical judgement (what they believe to be in the patient's best interests); or do anything that is unlawful (e.g. to take someone's life or practise euthanasia).

An Advance Statement can be made in writing or in discussion with a doctor. It will only come into effect when the particular circumstances specified within the statement are met, and the person is no longer able to make a decision or express their preference.

## **Why have I been asked to take part?**

You have been asked to take part in this study because you are aged 50 years old or over.

You may have been asked because you access a voluntary service for older people and/or carers, who have agreed to allow me to approach users of their service to take part in this study. Alternatively, you may have been given this information and questionnaire pack by a family member, friend, colleague or neighbour who thought you might be willing to share your views.

## **What will be involved if I take part in the study?**

If you are willing to take part, you will need to complete the enclosed questionnaire and provide some basic information about yourself. This information will only be used for the purpose of the study and it will not be possible to identify you from it. Completing the questionnaire and information sheet will take about 15 minutes. If you are willing to take part, it is very important that you complete ALL of the questions on both the questionnaire and the personal information sheet.

Whether or not you choose to complete the questionnaires, you will not be contacted again in relation to the study or asked to complete more questionnaires.

## **Will information obtained in the study be confidential?**

Your answers to the questions in this study are completely anonymous. It will not be possible to identify you from the information you provide. However, all of the information obtained as part of this study will be kept confidential.

## **What happens if I do not wish to participate or wish to withdraw from the study?**

Your participation in this study is entirely voluntary. Although your views would be valued, you should not feel under any pressure to complete or return the questionnaire if you do not wish to do so.

If you complete and return the questionnaire, this will be taken as your consent for your information to be used in this study. As your information is entirely anonymous and you cannot be identified, once you have returned your questionnaire it will not be possible to withdraw your information from the study.

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

Some people find it difficult or upsetting to think about end of life issues. If you experience distress or would like to talk to someone about the issues any of the questions raise for you, then it may be helpful to contact your GP for further advice, support or information.

## **Who is conducting this study?**

Daniella Wickett who is a Trainee Clinical Psychologist is undertaking this study, as part of her training. Dr. Marilyn Christie and Dr. Jan Oyeboode are supervising the study.

Daniella Wickett and Dr Marilyn Christie can be contacted at: University of Leicester, School of Psychology – Clinical Section, 104 Regent Road, Leicester, LE1 7LT. Tel: 0116 223 1648. Dr Jan Oyeboode can be contacted at: University of Birmingham, School of Psychology, Edgbaston, Birmingham, B15 2TT. Tel: 0121 414 4932.

## Appendix 8

### Feedback Form for Pilot Sample

## **Attitudes to Advance Statements Scale Feedback Sheet**

**Continue overleaf if required**

1. How did you feel about completing the questionnaire?
2. Did you find any of the questions distressing? If so, which questions?
3. Was the layout of the questionnaire easy to follow?
4. Were the instructions unclear or difficult to understand?
5. Were any of the questions unclear or difficult to answer? If so, which questions?
6. Do you feel that the questionnaire covered all aspects of this topic? If not what was missed?
7. Did the response options allow you to express your views?
8. Do you feel that you answered questions that were specifically about yourself any differently to questions that asked about your general attitude?
9. Is there anything that could be done to improve the information or questionnaire?
10. Any other comments

## Appendix 9

### Focus Group Interview Schedule

## Focus Group Interview Schedule

- The acceptability of the topic (attitudes to advance statements)
- The acceptability of the scale and the individual items within the scale
- Whether the scale items seem to be related to the topic (face validity)
- The readability and comprehensibility of the scale and the individual items within the scale
- Whether the scale allows respondents to express their views adequately (i.e. are the response formats sufficiently comprehensive and with meaningful response options)
- Whether any questions were confusing or difficult to respond to
- The comprehensibility and sufficiency of the supporting information and administration instructions for respondents
- How the supporting information and administration instructions influenced how respondents felt about completing the scale
- Any issues raised by completing the questionnaire or any effect that completing the scale has had upon them (including the emotional reactions that the scale or scale items generated)
- Any suggestions for improvements or changes to increase accessibility and acceptability of the scale (including attitudes or views that may not have been represented within the scale)

## Appendix 10

### Summary of Phase 1 Feedback

# Attitudes to Advance Statements Scale Feedback Sheet

## Results from questionnaires 1- 46

### 1. How did you feel about completing the questionnaire?

Ok (13)  
Fine (4)  
No problems (6)  
At ease (3)  
Interested/Interesting (2)  
Not sure (1)  
No response (1)  
Happy to do so (1)  
Comfortable (1)  
Quite happy to do it (1)

- Encouraged. Gives me an opportunity to express my opinion on advanced statements. Perplexed as to how on earth a scale can be developed on such an evolving subject.
- Able to complete it without feeling too subjective
- It concentrated the mind
- I treat it as an intellectual exercise
- Ok but a lot of death around for me at present so also a bit weird
- Too many questions
- Ok until well into it when I had to think a lot about the meaning of the question and consequently found it difficult to give an answer
- Fine, no problems at all
- It was fairly easy because it was all tick boxes
- 50/50
- Hadn't thought about this before but found it interesting – and possibly prompts me to do something. Q14 was the key question I felt. But I still wouldn't know how to go about it.
- I was happy to help someone's studies
- One step nearer to the inevitable end!

### 2. Did you find any of the questions distressing? If so, which questions?

No (41)  
No response (1)  
Not at all (1)  
Not really (1)

- I would wish to retain control of my circumstances wherever possible.
- No but thought provoking
- No though some are unclear and so perplexing
- I do not ever answer questions on ethnicity. Q1 was incomprehensible, also autonomy is a difficult word for many people to understand



- Q19 is thought provoking because when you're healthy it is almost impossible to imagine being terminally ill. And very difficult to imagine what one's response will be in that situation – so Q28 is difficult to answer.

### 3. Was the layout of the questionnaire easy to follow?

Yes (40)  
No (1)  
Some (1)  
Fairly (1)  
Reasonably (2)

- Some questions difficult to work out

### 4. Were the instructions unclear or difficult to understand?

No (35)  
Fine (1)  
Yes (4)  
Some (2)  
Clear enough (1)  
Ok (1)

- A little repetitive and does a blank response imply 'I prefer not to think about this'

### 5. Were any of the questions unclear or difficult or answer? If so, which questions?

No (31)  
No response (1)  
Most (1)  
? (1)  
Some (1)

- Q.31 Add in 'only if no directive was available'. Q.32 only if as legal as a will. Q30 person may no want treatment of any kind so should be adjusted regularly in light of developments and treatment outcomes.
- Q1. Might be better to start with a positive or neutral statement. It gives aq false impression of the intonation of the questionnaire. Q7. is a double question. Q10 do you need this as well as Q2 which is more neutral? Q32. I had to read a couple of times to get the sense right. Q33. this implies only one reason for not making an advance statement are there others (individual beliefs, family pressures etc.) and if so do they matter? Q36. double question and implies only one reason for not making an advance statement.
- Q1
- There was not enough detail about the finer points of an advanced statement. To feel I was answering the questions truthfully I would need a lot more information about an advance statement
- Q16 and Q22 were difficult
- Q1 dubious meaning? Jargon. Q11 meaning. Q20 protect who from what? Q32 surely the point of advance statements is to pre-empt incapacity to decide. Q37 add 'in conjunction with my family'
- Q1, Q4, Q6
- Q40 cannot be sure anyone I trust will be around when I die. Would be ideal if they were.

- Q5, Q7, Q8 – as you stated that doctors cannot 'act against their clinical judgement'. Q32 – I don't understand this question
- A number of the answers would really depend on what a specific advance statement said, especially questions which involved doctors
- Many of the questions had to be read several times and careful thought necessary to answer
- I found Q37 and Q38 difficult to answer. I agree with Q38 so I'm not happy at leaving all decisions to a doctor but there seemed no way of saying this. Q36 didn't give me a box to say that a person has a right to decide not to be a burden.

6. Do you feel that the questionnaire covered all aspects of this topic? If not what was missed?

Yes (27)

No (1)

No response (1)

? (1)

Seemed to (1)

Unknown (1)

I think so (2)

Ok (1)

- Possibly something about caring for someone who has an advanced directive/statement and how that feels
- Who people do (or should) consult with when making an advance statement or is it an autonomous process?
- I have heard of living wills previously but not advance statements so it is difficult to know if all aspects are covered. Is this something which would be filled in, in conjunction with doctors, or a general statement of preference/or circumstances which occur?
- The next of kin or closest relative should be made aware of an advance statement at the time of signing so there would be no surprise at time of illness
- Some examples of advance statements would make it easier to understand the subject. Some questions reply a ridiculous excess of detail. There is no indication of the legal framework.
- It's a big topic and I think a very important one. I can't think of any missing aspects
- As far as I know
- I do not know how established advance statements are. Are they written by doctors? Are lawyers involved? How different are advance statements from advance directives?
- People being coerced into making a statement by relatives etc or alternatively deterred from it by relatives/friends
- (Yes) if anything too many questions
- (Yes) very good
- A way of finding out more
- Any sense of timing. Should a statement be made at the age of 50? At the time you make a will? Or only when you become ill with a life threatening condition? If you make it aged 25 then Q33 becomes very relevant.

7. Did the response options allow you to express your views?

Yes (34)

Pretty well (1)

No response (1)

Not entirely (2)

In most cases (1)

Not always (1)

Reasonably (1)

Not really (1)

- With the limited amount of information given about advance statements, yes
- Not really, I follow Pope 'thou not bill but need'st strive officiously to keep alive'. Would that be a helpful AS?
- Not always – you often want to qualify what you say but on the whole they were good
- More or less. Ticking boxes does not generally get it quite right

8. Do you feel that you answered questions that were specifically about yourself any differently to questions that asked about your general attitude?

No (22)

Yes (12)

Not really (1)

I don't think so (1)

? (1)

Possibly (1)

Not sure (2)

Easier to answer (1)

- Questions seemed aimed at general attitudes (didn't feel too subjective)
- I answered every question as if it was specifically about myself
- I may have done so but do not feel that I did
- Only questions 13, 31 and 37 contain 'I'. Questions addressed to 'you' I read as addressed generally rather than to me
- Much easier to be certain of answers for myself. More difficult to consider what might be right for a parent/spouse/young person.

9. Is there anything that could be done to improve the information or questionnaire?

No (16)

No response (2)

Not sure (5)

? (3)

Not really (3)

Don't know (1)

Don't think so (2)

Maybe (1)

- Examples in the instructions would be clearer if they showed the same response to the same question in different ways rather than different responses in different ways e.g. all 'agree' or 'disagree'.
- I think that it is very good
- (No,) I realise that wanting more information about advanced statements before answering the questionnaire is like putting the horse before the cart
- Lots of 'ifs' and 'buts' on this subject, with which it is difficult to tailor simple multiple choice options

- I'm not qualified enough to answer this question
- It would be more certain to use a circle or tick - not both. (As above) Some concrete examples of AS would help.
- See above
- I was not familiar with the word 'advance statement' but I am familiar with the idea of writing down one's wishes. The question on whether one has been sad or unhappy in the last two weeks does not include a reason for this.
- No, not that I can think of
- Cannot think of any
- I could have done with a bit more information about advance statements. Currently how much weight do they carry? Or does it depend on the attitudes of the doctor and/or the relatives? Can you make it with variable conditions?
- Perhaps having decided an Advance Statement should be made – informing of the next step to be of value

## 10. Any other comments

- It would be interesting to see a proposed scale and comment on it.
- Good balance and good mix of sub topics with not too much repetition of 'loading questions'. Good luck with trying to interpret the responses!
- I had not thought about doing an advance statement, however I would not like to be a burden to my family therefore I might make one in the future
- Having seen my mother live with dementia, I would hate to live as she did in her last years (this by her own insistence). However, at what point would you draw the line if diagnosed with dementia? In the early stages, a reasonable quality of life is possible, but given that your reasoning and awareness are fading, how do you know when to call a halt? It is all very difficult, but it would have helped us greatly to have been able to discuss things with her.
- Having had to make decisions on behalf of my mother I think that advance statements are a good idea and feel that whenever possible they should be discussed with family members as well as healthcare professionals
- The term 'advance statement' is unfamiliar – if you wrote living wills most people would know what you were about. I am perhaps lucky in having 5 children in caring professions, three of them medically qualified. So the decision to allow my wife to do was taken jointly with the hospital doctor in charge. So I would be happy to leave the balancing of continuing existence and quality of life to them if I was unable to participate.
- My husband died of cancer. We completed a living will form from the natural death handbook but didn't lodge it with the doctor. However it did make it much easier for us to refuse a final operation and allow him to die in peace and dignity. Because we had discussed these possibilities when there was no pressure on us we knew we had made the right decision for him at the end. This has made it easier for me as well, knowing that it was what he wanted.
- Maybe people of a lower intelligence might find the lexis chosen a little hard to understand in some of the questions
- Like making a will, maybe a person making an advance statement should have legal advice and there were no questions about this. Many people need someone else to help write it down.
- I suppose at my age I don't think about the distant future too much but realise that one day the subject will have to be faced
- Very good
- I dislike and distrust doctors due to many past experiences so would not like to trust them carry out anything like an advance statement, would you?
- Don't trust doctors they bury their mistakes

## Appendix 11

### Summary of Focus Group Feedback

# **Focus Group Feedback**

**19<sup>th</sup> March 2007**

**Invited:** 31 participants from the University of Birmingham database of research volunteers

**Accepted:** 8 (5 others expressed an interest but were unable to attend due to other commitments)

**Attended:** 6 (3 women – aged, 59, 70 and 79 years old and 3 men - aged 59, 73 and 74 years old)

## **Main Points from Discussion**

### **Questionnaire provoked thought and discussion**

- Not something that people had thought about before – questionnaire was thought provoking. Good thing to have it brought to our attention.
- Not upsetting
- Made people reflect upon their own circumstances and consider the need to plan for the future
- Prompted discussions with families
- Quality of life seen as important
- Trust of doctors and relationship with GP an issue
- Needs to be a family decision. Difficulty in discussing this with families (or some family members)
- Can't imagine making one (getting round to it, knowing when is the right time)
- Risk of leaving it too late
- Good idea in principle but when do you do it? Do people discuss it?
- One comes away with a healthy disrespect for a doctor. I know my own feelings better than they do.

### **Need for more information**

- Some confusion about the term 'Advance statement' and overlap with Living Wills and Advance Directives. Many not heard of AS before – terminology thought to be unfamiliar to most people
- Difficulty in knowing what an advance statement could be – need for examples of what you might say and when you might say it
- Desire for clarity about how they are constructed and whether legal input was required
- Would like a TV programme or magazine article about it – something accessible. Many expressed an interest in receiving information about the results of the study.

## Questionnaire design - general

- Questions became more difficult as you went through and made you want to change your mind on earlier questions. Thought provoking
- Too many questions
- Often wanted to qualify responses
- Responses dependent on mood
- Filled it in as quickly as possible as the more you think about it – keep changing your mind
- Written response options for each question clearer than numbers or response at top of the page, particularly for older, older people.
- Can't see why two response options were offered. Mixed response about preference – go with whichever most people have done.
- More information needed on the front sheet of the questionnaire about AS
- 6 response options too many, often tempted to put it in the middle
- Unsure should be the middle response option – more logical order

## Questions that were unclear/difficult

- Q1 needs to be changed to a positive. Unclear what is meant by 'choice and autonomy'. Needs to be more concrete. 'Ability to choose' would be better
- Change all woulds, shoulds and coulds to present tense (e.g. can). Need to make questions more definite and concrete.
- Q11 – what does it mean not to care? Too vague. Need to make it explicit that mean families who might make decisions in their own interest or for their own gain
- Q14 – suggests that you make it at the same sort of time as a will (issue of timing)
- Q15 – unclear who would misuse an AS. Need to clarify by doctors or nurses.
- Q32 – AS are there to help others make a decision (self-contradictory to talk about ensuring person able to make decision as for use when unable to).
- Q33 – depends on circumstances. Could be improved
- Q36 – people have a right not to want to be a burden. It is not clear that the questions is about risk or feeling pressured into it
- Use of word 'burden' – emotional term. Others may not perceive it as a burden

## Participant Information Sheet

- Would like more information about the legal status? How binding it is on the medical profession? When do you make it? What sort of thing is it – examples? Who do you lodge it with – who does it go to? Use in emergency situations?
- Information given didn't influence responses and seemed objective. Potential disadvantage of included more information is that this might influence responses.
- Need to write 'please read this sheet first' on it

## Appendix 12

### Participant Information Sheet – Revised



## **Participant Information Sheet**

### **The Development of a Scale to Assess Attitudes to Advance Statements**

I would like to invite you to take part in a research study. Before you decide whether you would like to take part, please read the following information carefully. This information will explain the study to you, why you have been selected and what taking part in the study would involve for you. You are not obliged in any way to take part in this study, but if you choose to do so your participation would be greatly appreciated. Thank you.

#### **What is the purpose of the study?**

The purpose of this study is to develop a scale that will assess attitudes towards Advance Statements. The study focuses on the views of people aged 50 years old or more, as issues relating to end of life care may become increasingly important to people, for themselves or their family, as they get older. Although there has been research in this area, the views of this age group have often been overlooked.

For many people death and dying is difficult to think or talk about, and for some people there are few opportunities to discuss their concerns or preferences. It is hoped that once developed, this scale could be used to help doctors and other health care professionals to understand the needs and wishes of their patients and encourage more discussion about end of life issues and care.

#### **What is an Advance Statement?**

Although the term 'Advance Statement' may be unfamiliar to many people, the idea of talking about or writing down one's wishes for the future is common. An Advance Statement is a record of a person's preferences for future medical care and treatment. Advance Statements are designed to be used when a person is no longer able to make a decision or express their wishes due to mental or physical problems (such as confusion or unconsciousness). They are sometimes referred to as Living Wills.

Advance Statements often include a person's wishes about end of life care and the treatments they would or would not like to receive (for example resuscitation). Advance Statements can also be used to outline views and preferences about other things that are important in everyday life. An Advance Statement may contain requests for treatments not to be used or to be stopped in certain circumstances. A refusal of treatment is known as an Advance Directive.

Advance Statements that specify the kind of care a person would like to receive are not legally binding, but should be used to influence decisions about what is in the person's best interest. Advance Statements that refuse certain kinds of treatment (Advance Directives) are legally binding, as long as the person was able to take-in and weigh-up information and understand the broad consequences of the decision at the time it was made.

An Advance Statement cannot instruct a doctor to deny basic care (including food, water and hygiene); act against their clinical judgement (what they believe to be in the patient's best interests); or do anything that is unlawful (e.g. to take someone's life or practise euthanasia).

An Advance Statement can be made in writing or in discussion with a doctor. It will only come into effect when the particular circumstances specified within the Statement are met, and the person is no longer able to make a decision or express their preference.

## **Why have I been asked to take part?**

You have been asked to take part in this study because you are aged 50 years old or over.

You may have been asked because you access a voluntary service for older people and/or carers, which has agreed to allow me to approach users of their service to take part in this study. Alternatively, you may have been given this information and questionnaire pack by a family member, friend, colleague or neighbour who thought you might be willing to share your views.

## **What will be involved if I take part in the study?**

If you are willing to take part, you will need to complete the enclosed questionnaire and provide some basic information about yourself. This information will only be used for the purpose of the study and it will not be possible to identify you from it. Completing the questionnaire and information sheet will take about 15 minutes. If you are willing to take part, it is very important that you complete ALL of the questions on both the questionnaire and the personal information sheet.

Whether or not you choose to complete the questionnaires, you will not be contacted again in relation to the study or asked to complete more questionnaires.

## **Will information obtained in the study be confidential?**

Your answers to the questions in this study are completely anonymous. It will not be possible to identify you from the information you provide.

## **What happens if I do not wish to participate or wish to withdraw from the study?**

Your participation in this study is entirely voluntary. Although your views would be valued, you should not feel under any pressure to complete or return the questionnaire if you do not wish to do so.

If you complete and return the questionnaire, this will be taken as your consent for your information to be used in this study. As your information is entirely anonymous and you cannot be identified, once you have returned your questionnaire it will not be possible to withdraw your information from the study.

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

Some people find it difficult or upsetting to think about end of life issues. If you experience distress or would like to talk to someone about the issues any of the questions raise for you, then it may be helpful to contact your GP for further advice, support or information.

If you would like to know more about Advance Statements, Help the Aged have produced a booklet called 'Planning for Choice in End-of Life Care', which you might find helpful. If you have access to the internet this booklet can be downloaded from [www.helptheaged.org.uk](http://www.helptheaged.org.uk).

## **Who is conducting this study?**

Daniella Wickett who is a Trainee Clinical Psychologist is undertaking this study, as part of her training. Dr. Marilyn Christie and Dr. Jan Oyeboode are supervising the study.

Daniella Wickett and Dr Marilyn Christie can be contacted at: University of Leicester, School of Psychology – Clinical Section, 104 Regent Road, Leicester, LE1 7LT. Tel: 0116 223 1648. Dr Jan Oyeboode can be contacted at: University of Birmingham, School of Psychology, Edgbaston, Birmingham, B15 2TT. Tel: 0121 414 4932.

## Appendix 13

### Summary of Demographic Data for Phase 2 Sample

### Phase 2 Sample Characteristics

		Age 50-59	Age 60-69	Age 70-79	Age 80+	Unknown	Total
<b>Gender</b>	Male	21	23	11	6	1	62
	Female	34	26	25	18	2	105
	Missing	-	-	-	-	14	14
<b>Marital Status</b>	Single	7	1	1	1	-	10
	Married	34	26	15	5	8	88
	Remarried	8	9	2	-	5	24
	Separated	1	3	-	-	-	4
	Divorced	4	7	1	2	1	15
	Widowed	1	3	16	16	3	39
	Missing	-	-	1	-	-	1
<b>Ethnicity</b>	White British	48	47	34	24	17	170
	Asian	1	1	-	-	-	2
	Black	5	1	-	-	-	6
	Chinese	-	-	-	-	-	0
	Mixed – White and Asian	-	-	-	-	-	0
	Mixed – White and Black	-	-	-	-	-	0
	Other mixed background	-	-	-	-	-	0
	Any other ethnic background	1	-	2	-	-	3
<b>Religion</b>	Christian	36	42	32	20	13	143
	Buddhist	-	-	-	1	-	1
	Jewish	-	-	1	-	-	1
	Hindu	2	-	-	-	1	3
	Muslim	-	1	-	-	1	2
	Sikh	-	-	-	-	-	0
	Other	3	1	2	-	-	6
	None	14	5	1	3	2	25
<b>Education</b>	School – no qualifications	2	14	14	7	1	38
	School qualifications	4	6	3	5	2	20
	College or FE qualifications	14	8	6	7	5	40
	University qualifications	30	12	6	2	4	54
	Work based training/qualifications	4	9	7	1	5	26
	Missing	1	-	-	2	-	3

		Age 50-59	Age 60-69	Age 70-79	Age 80+	Unknown	Total
<b>Highest Occupation</b>	Professional	31	16	10	8	6	71
	Managerial or technical	14	11	9	2	7	43
	Non-manual skilled	5	4	5	5	3	22
	Manual skilled	2	6	2	1	-	11
	Partly skilled	1	-	4	4	-	9
	Unskilled	1	2	3	1	-	7
	Homemaker	1	7	2	3	1	14
	Missing	-	3	1	-	-	4
<b>Subjective health</b>	Very good	19	13	7	3	4	46
	Good	31	32	23	16	11	113
	Poor	4	2	5	3	2	16
	Very poor	-	-	1	1	-	2
	Missing	1	2	-	1	-	4
<b>Subjective mood</b>	Not at all unhappy	24	28	19	15	8	94
	Unhappy some of the time	30	19	16	9	7	81
	Unhappy most of the time	-	-	1	-	1	2
	Unhappy all of the time	-	2	-	-	1	3
	Missing	1	-	-	-	-	1
<b>Caring</b>	Previously carer	24	23	16	14	6	83
	Currently carer	5	7	4	-	1	17
	Involved in decision making	26	28	15	4	6	79
<b>Cognitive impairment</b>	Know someone with cognitive impairment	9	12	5	1	1	28
<b>Knowledge of Advance Statements</b>	No previous knowledge or awareness	19	17	19	13	7	75
	Some awareness but limited knowledge	26	22	12	11	7	78
	Moderate knowledge	9	6	4	-	3	22
	Missing	1	4	1	-	-	6
<b>Made an Advance Statement</b>	Thought about making one	12	12	5	8	8	45
	Discussed making one	1	-	1	-	1	3
	Have made one	-	3	6	-	0	9

## Appendix 14

### Attitudes to Advance Statements Scale – Phase 2 Version

# Attitudes to Advance Statements Scale

## Advance Statements

An Advance Statement is a record of a person's preferences for future medical care and treatment. Advance Statements are designed to be used when a person is no longer able to make a decision or express their wishes about their care due to mental or physical problems (such as confusion or unconsciousness). They are sometimes known as Living Wills.

Advance Statements often include a person's wishes about end of life care and the types of treatments they would or would not want to receive. Advance Statements can also be used to outline views and preferences about other things that are important to the person in everyday life. An Advance Statement may contain requests for treatments not to be used or stopped in certain circumstances.

Advance Statements that specify the kind of care a person would like to receive are not legally binding, but should be used to influence decisions about what is in the person's best interest. Advance Statements that refuse certain kinds of treatment are legally binding, as long as the person was able take-in and weigh-up information and understand the broad consequences of the decision at the time the decision was made. In addition, the refusal of treatment made in the Advance Statement must apply to the current situation.

An Advance Statement cannot instruct a doctor to deny basic care; act against their clinical judgement; or do anything that is unlawful.

## Instructions

Please read the questions on the following pages carefully and then circle the response option on the right that best expresses your view (as shown below). If you change your mind about your answer, simply cross it out and circle the response that you feel best expresses your view. Please answer ALL questions as honestly as possible.

## Examples

1	Advance Statements can help to guide doctors in making healthcare decisions	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
1	Advance Statements can help to guide doctors in making healthcare decisions	Strongly agree	<del>Agree</del>	Not sure	Disagree	Strongly disagree

## Attitudes to Advance Statements Scale

<b>1</b>	<b>Having an Advance Statement makes it more likely that your wishes for end of life care would be followed</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>2</b>	<b>A person's preferences about the type of care and treatments they want to receive may change over time</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>3</b>	<b>The preferences a person expresses in an Advance Statement are more important than the views and wishes of their family</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>4</b>	<b>Advance Statements specifying the care and treatments a person wants should be legally binding on doctors</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>5</b>	<b>Most doctors do not use Advance Statements in the way the person intended</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>6</b>	<b>It is difficult to talk about death and dying with people close to me</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>7</b>	<b>Making an Advance Statement could put your life at risk</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>8</b>	<b>The preferences a person expresses in an Advance Statement should be more important than the opinions of doctors</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>9</b>	<b>Making an Advance Statement encourages a person to think about what is important in life</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>10</b>	<b>A person's preferences about their future care may change in the face of serious illness</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>11</b>	<b>Advance Statements can protect the rights of a dying person whose family does not care</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>12</b>	<b>Making an Advanced Statement can ensure that I 'go my own way' at the end of my life</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>13</b>	<b>I would feel alarmed if a healthcare professional tried to talk to me about my future health care needs and preferences</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>



<b>14</b>	<b>Planning for end of life care with an Advance Statement is just as important as making a will</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>15</b>	<b>An Advance Statement could be misunderstood or misused by doctors and nurses</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>16</b>	<b>An Advance Statement helps to avoid family disagreements about healthcare decisions for their loved one</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>17</b>	<b>Advance Statements interfere with doctors' freedom to make the best decisions about a person's care</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>18</b>	<b>Advance Statements can help families to understand what their relative would want to happen in relation to end of life decisions</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>19</b>	<b>Discussing Advance Statements cannot help to prepare people for what might happen in the future</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>20</b>	<b>Advance Statements can help to protect people who are seriously ill from families who make care decisions for their own interests or benefit rather than the patient's</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>21</b>	<b>It is important for people to talk about what they want to happen at the end of their life</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>22</b>	<b>Advance Statements do not influence doctors' decisions about care</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>23</b>	<b>Making an Advance Statement gives a person a sense of control over the future</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>24</b>	<b>Advance Statements do not reduce the burden on families for making healthcare decisions</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>25</b>	<b>Advance Statements are a way of talking to doctors and nurses about future illness, care needs and preferences</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>26</b>	<b>There is no point in thinking about what might happen until something happens</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>27</b>	<b>By making an Advance Statement you can protect yourself from procedures you are absolutely sure you would never want</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>

28	The preferences for care and treatment expressed when you are well are unlikely to be the same when faced with the prospect of dying	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
29	Doctors can be trusted to make healthcare decisions when patients cannot choose for themselves	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
30	Making an Advance Statement to refuse treatment is risky because it could prevent a treatment that might help the person to recover	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
31	Writing an Advance Statement would be a good way to tell people what I want at the end of my life	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
32	Advance Statements ensure that a person's wishes influence end of life decision making	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
33	There is no point in making an Advance Statement because you cannot know what treatments may be available in the future	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
34	Advance Statements cannot totally rule out doubts for doctors and families about care and treatment decisions	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
35	Making an Advance Statement helps to reduce the stress of decision making at a time when a person is seriously ill or dying	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
36	There is a danger that people will be pressured into making an Advance Statement to prevent them from becoming a burden	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
37	If I were seriously ill and unable to make decisions for myself, I would expect the doctor to make the decision on my behalf	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
38	Unless a patient expresses their wishes in advance, doctors are likely to do more to keep them alive than many patients would want	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
39	Developing an Advance Statement provides an opportunity for patients, doctors and families to talk about end of life decisions	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
40	If possible, having someone you trust to make decisions on your behalf is better than making an Advance Statement	Strongly agree	Agree	Not sure	Disagree	Strongly disagree

**Thank you for completing this questionnaire.**  
**Please ensure that you have answered all of the questions.**

## Appendix 15

### Principle Components Analysis – Total Variance Explained Table

# Principle Components Analysis – Total Variance Explained Table

## Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	7.764	20.983	20.983	7.764	20.983	20.983
2	3.548	9.589	30.573	3.548	9.589	30.573
3	2.235	6.042	36.614	2.235	6.042	36.614
4	1.754	4.739	41.354	1.754	4.739	41.354
5	1.522	4.114	45.468	1.522	4.114	45.468
6	1.464	3.956	49.424	1.464	3.956	49.424
7	1.362	3.682	53.106	1.362	3.682	53.106
8	1.217	3.290	56.396	1.217	3.290	56.396
9	1.053	2.845	59.241	1.053	2.845	59.241
10	1.031	2.787	62.028	1.031	2.787	62.028
11	.959	2.593	64.621			
12	.927	2.504	67.126			
13	.872	2.357	69.482			
14	.803	2.170	71.653			
15	.764	2.066	73.718			
16	.730	1.973	75.692			
17	.712	1.924	77.616			
18	.680	1.837	79.453			
19	.642	1.735	81.188			
20	.595	1.609	82.796			
21	.572	1.547	84.344			
22	.529	1.431	85.774			
23	.518	1.399	87.173			
24	.500	1.351	88.524			
25	.459	1.240	89.763			
26	.438	1.184	90.947			
27	.410	1.107	92.055			
28	.393	1.061	93.116			
29	.369	.998	94.114			
30	.355	.959	95.073			
31	.339	.917	95.990			
32	.311	.841	96.831			
33	.294	.795	97.626			
34	.269	.727	98.353			
35	.262	.707	99.060			
36	.198	.534	99.594			
37	.150	.406	100.000			

Extraction Method: Principal Component Analysis.

## Appendix 16

### Varimax Rotated Component Matrix for Four Component Solution

**Rotated Component Matrix for Principle Components Analysis with varimax rotation  
of 37 items, specifying a four component solution**

**Rotated Component Matrix(a)**

	Component			
	1	2	3	4
Q23	.744	.168	.169	-.036
Q25	.724	.067	.213	-.101
Q27	.695	.180	.007	.044
Q31	.691	-.021	.260	.261
Q12	.648	.247	-.168	.031
Q32	.608	.081	.086	.148
Q1	.605	.170	.294	.006
Q14	.604	.196	-.205	.223
Q39	.573	-.235	.393	.288
Q3	.555	.219	.092	.238
Q11	.537	-.176	-.077	.153
Q20	.514	-.191	-.116	.424
Q18	.489	-.293	.278	.472
Q21	.470	-.069	-.005	-.006
Q16	.415	.331	.042	.160
Q9	.406	-.219	.244	.373
Q10	-.109	.671	-.094	.030
Q34	.205	.590	-.144	.125
Q40	.043	.588	.214	.093
Q30	.192	.576	.277	.135
Q28	.205	.489	.293	.038
Q15	-.129	.454	.225	-.042
Q17	.090	.436	.423	-.178
Q37	.294	.402	.146	.147
Q33	.162	.236	.597	.143
Q7	.074	.023	.568	.165
Q26	.230	.335	.555	-.088
Q13	.072	-.046	.504	-.213
Q19	.054	.133	.445	-.356
Q6	-.124	.185	.267	-.007
Q8	.210	.088	-.093	.605
Q4	.315	.187	-.304	.600
Q35	.359	-.023	.053	.507
Q38	-.011	.039	-.100	.457
Q36	-.175	.195	.334	.399
Q29	.062	.195	.155	.395
Q24	.090	.248	.300	.324

Extraction Method: Principal Component Analysis.  
Rotation Method: Varimax with Kaiser Normalization.  
a. Rotation converged in 7 iterations.

## Appendix 17

### Varimax Rotated Component Matrix for Five Component Solution

**Rotated Component Matrix for Principle Components Analysis with varimax rotation  
of 37 items, specifying a five component solution**

**Rotated Component Matrix(a)**

	Component				
	1	2	3	4	5
Q23	.743	.109	.185	.159	-.021
Q25	.719	.019	.255	.107	.001
Q27	.698	.128	.006	.124	-.060
Q31	.688	-.076	.057	.344	.205
Q12	.664	.303	-.180	-.214	.009
Q14	.615	.175	-.290	.064	-.036
Q32	.613	.075	-.029	.102	.119
Q1	.609	.172	.218	.101	.159
Q39	.576	-.149	.060	.067	.543
Q3	.559	.147	-.045	.334	.037
Q11	.542	-.105	-.198	-.174	.197
Q20	.518	-.180	-.371	.111	.212
Q18	.487	-.281	-.105	.300	.458
Q21	.468	-.077	.005	-.028	.009
Q16	.426	.300	-.057	.186	.019
Q35	.368	-.009	-.301	.251	.318
Q10	-.087	.671	-.093	.047	-.132
Q34	.229	.619	-.210	-.021	-.041
Q30	.209	.577	.118	.240	.140
Q15	-.108	.566	.131	-.145	.214
Q40	.057	.553	.118	.286	.020
Q28	.217	.479	.200	.207	.095
Q17	.098	.457	.424	.068	.112
Q6	-.116	.241	.174	.003	.199
Q4	.335	.197	-.631	.182	.138
Q19	.046	.116	.580	.041	.013
Q26	.225	.251	.525	.411	.073
Q13	.068	.011	.488	-.050	.263
Q8	.223	.081	-.464	.317	.233
Q29	.059	.040	-.056	.683	-.002
Q37	.295	.268	.089	.492	-.118
Q24	.094	.184	.049	.491	.180
Q38	-.011	-.062	-.319	.468	.001
Q7	.085	.162	.241	.002	.609
Q36	-.153	.338	-.092	.060	.573
Q9	.414	-.109	-.122	.005	.538
Q33	.167	.246	.351	.330	.374

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 10 iterations.



## Appendix 18

### Varimax Rotated Component Matrix for Three Component Solution

**Rotated Component Matrix for Principle Components Analysis with varimax rotation  
of 37 items, specifying a three component solution**

**Rotated Component Matrix(a)**

	Component		
	1	2	3
Q31	.768	.133	.064
Q39	.731	-.037	.178
Q18	.700	-.095	-.015
Q23	.673	.241	.143
Q25	.660	.144	.227
Q27	.619	.222	-.036
Q20	.612	-.106	-.316
Q32	.605	.161	-.023
Q1	.584	.274	.218
Q9	.573	-.055	.007
Q3	.562	.307	-.085
Q11	.553	-.128	-.128
Q14	.548	.209	-.313
Q12	.526	.235	-.178
Q35	.502	.102	-.248
Q21	.438	-.040	.010
Q16	.382	.378	-.094
Q30	.176	.653	.082
Q40	.012	.632	.053
Q10	-.222	.611	-.168
Q28	.174	.558	.161
Q34	.098	.556	-.253
Q17	.036	.496	.397
Q15	-.163	.473	.155
Q37	.275	.462	-.011
Q33	.271	.412	.373
Q24	.202	.375	.026
Q36	-.001	.330	.015
Q29	.179	.297	-.126
Q6	-.094	.235	.199
Q4	.385	.223	-.613
Q19	.002	.181	.551
Q13	.106	.052	.535
Q26	.235	.458	.463
Q8	.349	.178	-.436
Q7	.229	.200	.360
Q38	.108	.091	-.351

Extraction Method: Principal Component Analysis.  
Rotation Method: Varimax with Kaiser Normalization.  
a. Rotation converged in 6 iterations.

## Appendix 19

### Varimax Rotated Component Matrix for Two Component Solution (37 Items)

**Rotated Component Matrix for Principle Components Analysis with varimax rotation  
of 37 items, specifying a two component solution**

**Rotated Component Matrix(a)**

	Component	
	1	2
Q31	.736	.195
Q18	.676	-.047
Q39	.663	.098
Q20	.662	-.205
Q23	.632	.321
Q27	.622	.216
Q14	.619	.069
Q32	.601	.168
Q25	.594	.275
Q3	.584	.264
Q12	.567	.155
Q11	.558	-.139
Q35	.552	.003
Q9	.550	-.010
Q4	.535	-.072
Q1	.530	.381
Q8	.454	-.029
Q21	.419	-.003
Q16	.416	.311
Q29	.222	.212
Q38	.195	-.080
Q26	.144	.637
Q17	-.030	.626
Q30	.191	.623
Q40	.037	.581
Q28	.165	.577
Q33	.198	.555
Q15	-.166	.479
Q10	-.136	.443
Q19	-.119	.421
Q37	.298	.418
Q34	.190	.374
Q7	.147	.361
Q24	.212	.354
Q13	-.022	.307
Q36	.016	.297
Q6	-.124	.295

Extraction Method: Principal Component Analysis.  
Rotation Method: Varimax with Kaiser Normalization.  
a. Rotation converged in 3 iterations.

## Appendix 20

### Varimax Rotated Component Matrix for Two Component Solution (33 Items)

**Rotated Component Matrix for Principle Components Analysis with varimax rotation  
of 33 items, specifying a two component solution**

**Rotated Component Matrix(a)**

	Component	
	1	2
Q31	.723	.226
Q18	.681	-.041
Q39	.671	.099
Q20	.667	-.196
Q23	.619	.363
Q14	.614	.098
Q27	.609	.259
Q32	.591	.201
Q25	.584	.319
Q3	.571	.285
Q12	.571	.178
Q11	.570	-.126
Q9	.565	-.021
Q35	.550	.009
Q4	.535	-.073
Q1	.521	.407
Q8	.452	-.034
Q21	.431	.004
Q16	.397	.342
Q26	.123	.645
Q17	-.052	.635
Q30	.169	.628
Q40	.014	.585
Q28	.154	.560
Q33	.182	.553
Q15	-.176	.477
Q10	-.157	.437
Q19	-.133	.435
Q37	.276	.425
Q34	.179	.380
Q24	.197	.347
Q7	.149	.333
Q13	-.019	.296

Extraction Method: Principal Component Analysis.  
Rotation Method: Varimax with Kaiser Normalization.  
a. Rotation converged in 3 iterations.

## Appendix 21

### Varimax Rotated Component Matrix for Two Component Solution (28 Items)

**Rotated Component Matrix for Principle Components Analysis with varimax rotation  
of 28 items, specifying a two component solution**

**Rotated Component Matrix(a)**

	Component	
	1	2
Q31	.735	.213
Q39	.683	.063
Q18	.680	-.076
Q20	.659	-.236
Q23	.634	.362
Q27	.619	.255
Q14	.609	.088
Q32	.598	.179
Q25	.593	.308
Q3	.580	.286
Q12	.576	.171
Q9	.571	-.051
Q11	.569	-.143
Q35	.539	-.057
Q1	.534	.394
Q4	.525	-.078
Q8	.452	-.049
Q21	.438	.011
Q26	.147	.657
Q17	-.032	.631
Q30	.185	.624
Q28	.177	.581
Q40	.027	.571
Q33	.209	.557
Q19	-.110	.457
Q37	.289	.449
Q15	-.162	.447
Q10	-.147	.445

Extraction Method: Principal Component Analysis.  
Rotation Method: Varimax with Kaiser Normalization.  
a. Rotation converged in 3 iterations.



## Appendix 22

### Attitudes to Advance Statements Scale – Final 28-item Version

# Attitudes to Advance Statements Scale

## Advance Statements

An Advance Statement is a record of a person's preferences for future medical care and treatment. Advance Statements are designed to be used when a person is no longer able to make a decision or express their wishes about their care due to mental or physical problems (such as confusion or unconsciousness). They are sometimes known as Living Wills.

Advance Statements often include a person's wishes about end of life care and the types of treatments they would or would not want to receive. Advance Statements can also be used to outline views and preferences about other things that are important to the person in everyday life. An Advance Statement may contain requests for treatments not to be used or stopped in certain circumstances.

Advance Statements that specify the kind of care a person would like to receive are not legally binding, but should be used to influence decisions about what is in the person's best interest. Advance Statements that refuse certain kinds of treatment are legally binding, as long as the person was able to take in and weigh up information and understand the broad consequences of the decision at the time the decision was made. In addition, the refusal of treatment made in the Advance Statement must apply to the current situation.

An Advance Statement cannot instruct a doctor to deny basic care; act against their clinical judgement; or do anything that is unlawful.

## Instructions

Please read the questions on the following pages carefully and then circle the response option on the right that best expresses your view (as shown below). If you change your mind about your answer, simply cross it out and circle the response that you feel best expresses your view. Please answer ALL questions as honestly as possible.

## Examples

1	Advance Statements can help to guide doctors in making healthcare decisions	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
---	---	----------------	-------	----------	----------	-------------------

1	Advance Statements can help to guide doctors in making healthcare decisions	Strongly agree	<del>Agree</del>	Not sure	Disagree	Strongly disagree
---	---	----------------	------------------	----------	----------	-------------------

## Attitudes to Advance Statements Scale

<b>1</b>	Having an Advance Statement makes it more likely that your wishes for end of life care would be followed	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>2</b>	The preferences a person expresses in an Advance Statement are more important than the views and wishes of their family	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>3</b>	Advance Statements specifying the care and treatments a person wants should be legally binding on doctors	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>4</b>	The preferences a person expresses in an Advance Statement should be more important than the opinions of doctors	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>5</b>	Making an Advance Statement encourages a person to think about what is important in life	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>6</b>	A person's preferences about their future care may change in the face of serious illness	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>7</b>	Advance Statements can protect the rights of a dying person whose family does not care	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>8</b>	Making an Advanced Statement can ensure that I 'go my own way' at the end of my life	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>9</b>	Planning for end of life care with an Advance Statement is just as important as making a will	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>10</b>	An Advance Statement could be misunderstood or misused by doctors and nurses	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>11</b>	Advance Statements interfere with doctors' freedom to make the best decisions about a person's care	Strongly agree	Agree	Not sure	Disagree	Strongly disagree

<b>12</b>	<b>Advance Statements can help families to understand what their relative would want to happen in relation to end of life decisions</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>13</b>	<b>Discussing Advance Statements cannot help to prepare people for what might happen in the future</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>14</b>	<b>Advance Statements can help to protect people who are seriously ill from families who make care decisions for their own interests or benefit rather than the patient's</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>15</b>	<b>It is important for people to talk about what they want to happen at the end of their life</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>16</b>	<b>Making an Advance Statement gives a person a sense of control over the future</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>17</b>	<b>Advance Statements are a way of talking to doctors and nurses about future illness, care needs and preferences</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>18</b>	<b>There is no point in thinking about what might happen until something happens</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>19</b>	<b>By making an Advance Statement you can protect yourself from procedures you are absolutely sure you would never want</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>20</b>	<b>The preferences for care and treatment expressed when you are well are unlikely to be the same when faced with the prospect of dying</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>21</b>	<b>Making an Advance Statement to refuse treatment is risky because it could prevent a treatment that might help the person to recover</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>22</b>	<b>Writing an Advance Statement would be a good way to tell people what I want at the end of my life</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly disagree</b>

<b>23</b>	Advance Statements ensure that a person's wishes influence end of life decision making	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>24</b>	There is no point in making an Advance Statement because you cannot know what treatments may be available in the future	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>25</b>	Making an Advance Statement helps to reduce the stress of decision making at a time when a person is seriously ill or dying	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>26</b>	If I were seriously ill and unable to make decisions for myself, I would expect the doctor to make the decision on my behalf	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>27</b>	Developing an Advance Statement provides an opportunity for patients, doctors and families to talk about end of life decisions	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<b>28</b>	If possible, having someone you trust to make decisions on your behalf is better than making an Advance Statement	Strongly agree	Agree	Not sure	Disagree	Strongly disagree

**Thank you for completing this questionnaire.  
Please ensure that you have answered all of the questions.**