



# Understanding the Dynamics of Decision-Making and Choice: A Scoping Study of Key Psychological Theories to Inform The Design and Analysis of the Panel Study

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# Abstract

At the heart of SPRU's DH-funded programme of research is a qualitative longitudinal Panel Study that aims to examine the choices that older people, disabled young people, disabled adults and their carers make about their services and support; how these choices change over time; and the implications for their experience of independence.

To inform the Panel Study and drawing mainly on psychological research, we conducted a review of the main theoretical models of decision-making and choice. Unlike systematic reviews, the review did not set out to identify and evaluate the existing evidence base. Instead the review identifies the main areas of psychological theory and research relevant to choices about welfare services; and assesses the implications of these for the design and analysis of the Panel Study.

The review covers the main theories of judgement, decision-making and choice; the factors such as emotion, which affect choice and decision-making; and evidence on specific decision-making situations, including joint decision-making with another person, making choices on behalf of someone else and decision-making within close relationships.

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# Understanding the Dynamics of Decision-making and Choice: A scoping study of key psychosocial theories to inform the design and analysis of the Panel Study

# Section 1: Introduction

This paper provides an overview of some of the main psychological models of decision-making and choice and assesses their relevance to disabled and chronically ill young people and adults, older people and carers, and to the choices they make about social care and related support services. It addresses three questions:

- What are the processes by which people make choices, and what constraints shape these processes?
- What are the personal and environmental preconditions for exercising choice and how do these conditions affect choice?
- How far are these insights relevant to choices about social care and related support services on the part of people with impairments or disabilities and their carers?

The purpose of conducting this review was to inform aspects of research design and the analysis of data collected during the DH funded Panel Study on 'Choice and Change Across the Lifecourse'.

The paper is divided into three sections:

- Descriptions of key theoretical models (Section 2);
- Discussion of factors which affect choice or decision-making: emotion, personality, and cognitive capacity (Section 3);
- An examination of what is understood about some specific decision-making situations: making decisions on behalf of someone else; shared decision-making; and decision-making in close relationships (Section 4).

A number of theoretical approaches were explored with regard to their potential usefulness to the panel study (details of the methods are contained in the Appendix). From that preliminary exploration, three theoretical models will be examined in Section 2, all of which are concerned with choice or decision-making situations which are pertinent to the panel study and the above questions:

• The Information-Processing Approach, in which we focus mainly on the Adaptive Decision Maker Framework which is concerned with how people choose between alternatives when none is clearly the 'best option'. In this section we also report other bodies of research on the heuristics or strategies

we use to make decisions; and describe what is understood about the role of unconscious thought processes in decision-making.

- Prospect Theory, which is concerned with making decisions involving risk or uncertainty.
- Theory of Reasoned Action and Theory of Planned Behaviour, which are both concerned with the relationship between attitudes and behaviours in the context of making choices.

## The process of choice

Choice is the outcome of a process which involves assessment and judgement; that is, the evaluation of different options and making a decision about which option to choose. In order for these processes to take place and a choice to be made, there need to be two or more alternatives from which to choose. In addition, these alternatives should have some positive value; in this sense a 'choice' between something which is definitely desired and something which is definitely not desired is not a true choice. The processes entailed in choice all involve cognition, and psychological theories concentrate on explaining how people make choices, in particular the cognitive processes that underlie choice. Empirical research on how people make decisions and choices covers a range of different people in different situations, for example from clinicians treating patients or investors and financial experts, to students taking part in psychological experiments. However, it suggests that different people in different situations frequently think about decisions in the same way, reflecting the fact that human beings have a common set of cognitive skills (Hastie and Dawes, 2001). These cognitive skills and their limitations are also influential in constraining choices so that choice making in reality varies from what may be seen as ideal and logical.

# Section 2: Theories of Judgement, Decision-making and Choice

Theories regarding judgement, decision making and choice generally fall into two categories: normative theories of cognition and descriptive theories of cognition. Normative theories are concerned with 'how we should or ought to reason, make judgements and take decision' (Over, 2004). Theories falling into this category include formal logic, probability theory, and decision theory. Descriptive theories set out to describe how people actually think when making decisions and have empirical evidence to support them. It is this latter set of theories that we are concerned with in this paper, in order to inform our aim of exploring the processes through which people make choices.

# The Information Processing Approach to decision research (Payne and Bettman, 2004)

The Information Processing Approach to decision research can be traced back to Simon (1955) and the notion of bounded rationality, that is, humans are 'bounded' by constraints in the environment (for example, information costs), and in the mind (for example, limited memory); these constraints shape people's behaviour. Research taking this approach initially focused on cognitive aspects of decision-making; more recently it has expanded to include emotional and 'ease of justification' aspects of decision-making.

The approach is based on the following assumptions:

- We are highly selective about what information we attend to and how it is used.
- Acquiring and processing information has cognitive and/or emotional costs.
- We use simplification mechanisms (heuristics) to select and process information: lots of different heuristics have been identified.
- Heuristics are chosen on the basis of the nature of the task problem.
- Beliefs and preferences are often constructed/generated through the process of decision-making, as opposed to individuals having known, well-defined preferences which they bring to a decision-making situation.

The approach is primarily concerned with understanding controllable, conscious processes<sup>1</sup> (System 2 thinking). However, it has recently been acknowledged that more work is needed to understand the interaction/impact of System 1 thinking on System 2 thinking in decision-making. Within this approach is the Adaptive Decision

<sup>&</sup>lt;sup>1</sup> Thinking can be conceived as being on a continuum – intuitive, relatively unconscious (System 1) through to analytic, controllable, conscious (System 2). See page 9 for further details.

Maker Framework, which is concerned with choice among alternative courses of action.

## The Adaptive Decision-Maker Framework

The Adaptive Decision-Maker Framework is an example of the Information Processing Approach to decision-making. It is concerned with how individuals choose between different courses of action, in particular, in choice situations where no single alternative (or option) is best on all attributes (or qualities, features). These sorts of decisions are known as preferential choice problems.

The Adaptive Decision-Maker Framework argues that preferential choice problems are generally solved through a process of information acquisition and evaluation about the alternatives and their attributes. The attributes by which the different options are defined will vary according to:

- their desirability to the decision-maker;
- the uncertainty of actually receiving the attribute value;
- the willingness of the decision-maker to accept a loss on one attribute for gain on another attribute.

The following example illustrates the role of attributes in the decision-process put forward by the Adaptive Decision-Maker Framework.

## Figure 1: An illustration of the role of attributes in the decision process

An individual is weighing up the merits of various holiday destinations.

#### The desirability of the attributes to the decision-maker

The following attributes are important to this individual:

- Weather: very warm and sunny
- Culture: unspoilt, not touristy
- Journey time: no more than 10 hours
- Personal safety: holidaying alone, wants to feel safe
- Location: seaside but near mountains.
- Language: native language must be Spanish or English widely spoken.

Other attributes of these destinations (for example, type of local cuisine, opportunities for shopping) are not important to this individual. In addition, two of the destinations have 'unique' desired attributes not shared with the other options (one offers the opportunity of visiting a country never visited before, another has relatives living in the vicinity thus affording the chance to visit them).

#### The uncertainty of actually receiving the attribute value

Some of the desired attributes are more certain than others. Thus the location and language of the various destinations can be carefully researched in advance and the individual can be certain about these. There is less certainty with respect to other attributes and the level of certainty may vary between alternatives. Thus, whilst for one destination there is 90% certainty that it will be 75<sup>o</sup>F and will have 8 hours sunshine each day, another destination may be warmer and sunnier but the weather is less predictable and there is only a 75% chance of temperatures of at least 80<sup>o</sup>F and 10 hours sunshine per day. Another source of uncertainty in this situation is that the individual is somewhat dependent on other people's judgements as to how 'touristy' each destination is.

## Willingness to accept loss on one attribute for gain on another

Finally, in making a decision, this individual is prepared to forgo a journey time of less than 10 hours in order to gain a greater guarantee of personal safety.

Theorists argue that there are ranges of strategies (heuristics) someone might use for solving a multi-attribute choice problem. The strategy chosen will depend on the demands of the task (for example, the number of alternatives to be considered), how accurate the decision has to be, and individual differences. In other words, different individuals will chose different strategies, and this will also vary according to the importance of the choice-making situation to that individual (Beach and Mitchell, 1978; Payne, 1976).

Some strategies will use all relevant information, others will use information in a more limited and often very selective fashion. Some strategies focus on the

alternatives and process each one in turn, other strategies are more attributefocused (that is, the values of several alternatives on a single attribute are examined before information on another attribute is considered).

Simpler decision processes (heuristics) save on cognitive effort by only processing some of the decision-relevant information. In experimental conditions they have been shown to work less and less well the greater the number of important attributes. Researchers have identified and named different types of heuristics.

- Lexographic strategy (LEX): here the strategy is to identify and chose the alternative with the best value on the most important attribute.
- Satisficing Strategy for Decisions (SAT) (Simon, 1955): this heuristic involves each attribute's value for the alternative/option currently under consideration being compared to a pre-determined cut-off level for that attribute. If any attribute fails to meet the cut-off level, the option is rejected and the next option considered. Once a satisfactory alternative has been identified, that alternative is chosen (so it might not be the 'best'). If no option passes the cut-off, the levels can be relaxed and the process repeated.
- Elimination By Aspects (EBA) (Tversky, 1972): this is a commonly used heuristic containing elements of LEX and SAT. EBA eliminates options that do not meet a minimum cut-off value for the most important attribute or do not have a desired aspect for the most important attribute. The elimination process is repeated for the second most important attribute and continues until a single option remains. The order in which attributes are considered reflects the decision-maker's basic values. Theorists argue that 'decision accuracy' is affected by the attributes used (for example, selectively attending to irrelevant, or relatively irrelevant, attributes).

Researchers have also shown that decision-makers may combine choice strategies. A typical combined strategy might involve elimination of some alternatives in an initial 'broad brush' viewing of the options, followed by a second phase in which the remaining options are analysed in more detail.

Laboratory-based research on the effectiveness/accuracy of heuristics has shown that heuristics can result in highly accurate/high quality decisions with substantial savings in cognitive effort. However, no single heuristic does well across all environments and people therefore need a repertoire of heuristics. Researchers have also shown that, in cases of substantial time pressure, the simple LEX rule is often best in terms of maintaining decision accuracy. That is, it is best to examine some, albeit limited, information about each option under severe time pressure than to examine some options in depth and not examine others at all.

## Use of different choice strategies

There has been a lot of research looking at how we use or choose different choice strategies. Key (relevant) findings from this work are as follows:

- People process information quite differently if faced with many alternatives (four or more) than if faced with just two or three alternatives.
- People have a repertoire of decision strategies and sometimes plan in advance how to solve a problem (based on the evidence of what the task involves).
   However, sometimes strategy selection is bottom-up, with little or no constructive awareness of a strategy being selected.
- Furthermore, people adjust their processing during the course of solving a problem in an "opportunistic" fashion as they learn more about the structure of the decision.
- Decision strategies with high cognitive effort are more likely to be used when decision accuracy is prioritised over saving cognitive effort.
- In laboratory-based simulations, people who shift strategies in response to the demands of the decision or time constraints perform better.
- Time pressure (that is, a decision must be made by a certain point in time) has been shown to be one of the most important decision task variables. Errors in judgement can be made from either deciding too soon (rush-to-judgement) or from delaying decisions too long.
- Individual differences in values will define what constitutes an accurate or high quality decision (that is, whether or not an individual is happy/satisfied with the decision made). It is also likely that we adjust our 'quality standards' as a function of task demands (such as time pressure, complexity of the decision).

## The role of emotion and other goals in the choice-making process

The majority of research and theorising on decision-making has very much been approached in terms of understanding decision-quality (or accuracy) and minimising cognitive effort. More recently, the Adaptive Decision-Maker Framework has been extended to include emotion and other goals for a decision because it is clear that strategy selection and other aspects of decision behaviour are not just determined by cognitive effort and decision accuracy. The other goals (or desired outcomes of a decision) are often developed constructively 'on the spot' and can affect the processes of the decision and the products of the decision.

## The Choice Goals Framework for Decision-making

Bettman *et al.* (1998) developed a choice goals framework for decision-making. In addition to maximising decision quality and minimizing cognitive effort, they argued there were two further meta-goals for choice namely:

- Minimizing the experience of negative emotion while making the decision and afterwards;
- Maximising the ease of justification of a decision to oneself and to others.

The relative importance of these meta-goals, and other goals, will vary according to the specific choice-making situation. It would appear that factors such as the importance and irreversibility of the decision affect the way these meta-goals are prioritised. Minimising negative emotion and ease of justification are clearly potentially salient issues for the Panel Study. In terms of the latter, Bettman *et al.*, 1998 argues that needing to justify a decision may lead to the use of decision strategies which are based on easily seen and communicable relationships among options (relational heuristics). Work on the impact of minimising negative emotion within the decision-making process is more developed and draws on other pre-existing theories and research on how negative emotion. These are described below.

## Minimising negative emotion

Not all decisions evoke emotional responses, but sometimes people face emotionladen choices.

There are contrasting views on the potential impact of negative emotion on the decision-making process:

- Hancock and Warm (1989) argue that emotion interferes with decision processes and degrades cognitive performance (observable in increased time to make a decision and more negative error). This argument would suggest that decision situations where negative emotions are aroused are, in a sense, analogous to highly complex decision situations. One would therefore expect individuals to adapt to them in the same way as they adapt to complex decision situations, that is by shifting to simpler, easier to implement decision strategies (Payne and Bettman, 2004).
- An alternative view draws on coping theory, which argues that people directly adapt to the negative emotion in one of two ways (Folkman and Lazarus, 1988):
  - a. Problem-focused coping. Adopting this strategy will mean the person tries to solve the problem as well as possible, with the negative emotion being seen to indicate the importance of the decision to the individual.
  - *b.* Emotion-focused coping. This way of managing negative emotion will mean action is taken directly to minimise emotion by changing the amount or content of thought about the decision. This could be achieved in a

variety of ways: refusing to make any decision (Anderson, 2003); letting another person make the decision for you; showing an increased preference for the status quo option or any other related option that is easier to justify to oneself (Luce, 1998); not avoiding the decision altogether but instead avoiding whatever aspects of the decision one finds most distressing.

One type of decision which has the potential to arouse negative emotions are when trade-offs have to be made between two highly valued things. An example of an emotionally difficult trade-off is life sustaining, but invasive and possibly painful, treatment versus quality of life. Tetlock (2002) talked about sacred versus profane tradeoffs and noted that some tradeoffs are taboo – people just do not go there. Because making trade-offs can generate negative emotions, individuals may cope with emotion-laden decisions by avoiding strategies which use trade-offs (of one attribute against another) and instead use non-compensatory strategies.

The negative emotions experienced while making a choice involving difficult tradeoffs have been shown to impact on strategy selection and decision-making. For example, research has found that emotion-laden choices are characterised by increased amounts of processing and avoidance of trade-offs. In addition, evidence suggests that decision-makers tend to confront between-attribute trade-offs explicitly when attributes are relatively low in emotional trade-off difficulty, but they avoid these explicit trade-offs when attributes are higher in emotional trade-off difficulty.

The role of emotion in making choices will be further discussed in Section 3.

## The dual process views of thinking

The dual process views of thinking are another extension of the information processing perspective. A number of researchers have argued that there are two modes of thinking (Hogarth, 2001; Kahnemann and Frederick, 2002; Sloman, 1996): System 1 thinking (intuitive) and System 2 thinking (analytical). Rather than being distinct, it is thought they probably represent the ends of a continuum (Hammond, 1996). Simon (1983) also argued that any kind of serious, complex thinking employs both analytical and intuitive thought.

System 1 thinking is relatively unconscious, relatively independent of language and generates a feeling of certitude. It is related to intuition and allows rapid, automatic and relatively effortless decision-making (Slovic *et al.*, 2002). In contrast, System 2 thinking is controllable, conscious, constrained by working memory, rule-based, serial, develops with age and is vulnerable to aging, is related to language and is less characterised by feelings of certitude. It is commonly called analytic thinking.

While System 2 thinking covers the higher level cognitive, attention-demanding, information processing activities that characterise much decision-making (and which have been the main focus of research), there is a growing awareness that information processing below the level of consciousness (that is, System 1 thinking) may have far greater impact on judgements and choices than previously realized (Bargh and Chartrand, 1999; Hogarth, 2001).

There are a number of hypotheses about how System 1 and System 2 thinking interact. The Correction model proposes that an initial judgement is quickly arrived at via System 1 and that this judgement may then either be expressed immediately, or confirmed and corrected by more effortful, conscious System 2 processing (for example, Cobos *et al.*, 2003). Some argue that System 2 thinking is only used to deal with more unusual cases. Hogarth (2001) argues that a mark of intelligence is learning when intuition (System 1) is erroneous and how to use deliberate (System 2) thought appropriately to make correct judgements.

Others have suggested that System 2 thinking is used in situations either where the individual cannot rely on past experience or with respect to events happening in the future. In contrast, Gilbert and Gill (2000) argue that the mode of information processing is selected on the basis of factors such as cognitive load or time pressure; System 1 thinking is selected when cognitive load is high or time is short.

Research has compared the efficacy of these two ways of thinking in decisionmaking. Dijksterhuis (2004) reports a set of experiments testing two hypotheses:

- When making complex decisions, a brief period of unconscious thought will lead to a better decision compared with conditions under which unconscious thought is prevented.
- When making complex decisions, conscious thought is inferior relative to unconscious thought.

The results confirmed the hypotheses, showing that participants in the unconscious thought condition (performing a distracter task before making the decision) generally performed better than those in the conscious thought condition (asked to think very carefully about the information they had been given before making a decision).

Dijksterhuis then proposed that unconscious thought is active: it organises information in the memory by polarising the alternatives and/or by clustering pieces of information that relate to the same alternative. Two further experiments tested this hypothesis and found evidence for both these processes under the unconscious thought condition, but less evidence under the conscious thought condition. Indeed conscious thought seemed to prevent almost completely meaningful clustering.

In these experiments, participants were told that they had to decide between various alternatives before they engaged in conscious or unconscious thought. It may be that this is crucial to ensuring that unconscious thought is directed at the particular task.

These findings have relevance to the conditions under which users and carers make choices. How much information do they have? Do they try to think through and weigh up all the information? Is this possible, given limited processing capacity? Do they come to decisions after stepping back from the information and thinking about something else? How do circumstances affect decision making (for example, limits on capacity through stress and emotion or an inability to step back)?

## The usefulness of the decision-maker framework for the Panel Study

This is a model which would appear to be highly relevant to the project as it is concerned with choices between courses of action where none of the options is optimal in terms of all its attributes. Furthermore, proponents of this approach suggest it is particularly relevant with respect to unusual situations, where the individual cannot 'go' on past experience, and with regard to decisions re future events. Finally, there appears to be relatively robust evidence to support the framework.

- The approach is primarily concerned with cognitive processes and raises questions about the impact of learning difficulties/cognitive impairment/memory impairment and ability/quality/accuracy of decision-making. This will be an issue for the Panel Study in situations where there is a decline or loss of cognitive abilities: how do individuals involved in those situations try to support continued involvement in decision-making (for example, by changing the amount and way information is provided); how are judgements made about someone's ability to take decisions; whether certain decisions are judged too complicated etc.
- The recent shift to considering issues of negative emotion and 'ease of justification' on the process and outcomes of decision-making suggests the importance of exploring those issues with Panel Study participants. For example, do people avoid certain pieces of information in making a decision because they are too emotionally difficult? To what extent does the notion of 'ease of justification' impact on the decision process, bearing in mind that many of the decisions we will be exploring are relatively 'public' (if not in the decision process itself, then in terms of the outcome of a decision)? It is important that we explore these other meta-goals in the interviews.
- Another interesting research finding is that which suggests people's preferences for/beliefs about things are often constructed (not merely revealed) in the course of decision-making. Perhaps this is particularly relevant where entirely novel situations are being encountered (for example, through sudden onset or degenerative conditions). It would also be good to explore the way decision-making means that the beliefs/views which people hold in quite an

objective sense might be challenged and changed during a decision-making episode.

- The emphasis on information raises issues about access to information, the way information is provided and how that may skew a decision. The phenomenon of 'framing' (a key aspect of Prospect Theory that we discuss later in this paper) links nicely to this.
- Finally, the decision-maker framework acknowledges numerous sources of individual difference to account for differences in the way individuals make a decision and in the decision made (for example, cognitive ability; choice of heuristics; preferred styles of coping with negative emotion; social context in which having to justify oneself).

## Other heuristic models

The purpose of a heuristic model is to describe the actual process of decision making; observational and empirical evidence on how people make decisions underlies these models. The models specify a process rule; the capacities the rule exploits to be simple; and the kinds of problems the heuristic can solve. Common models are recognition heuristics, heuristics based on reasons, and social heuristics.

The basis of heuristics is that we don't know the optimal solution to problems but can use heuristics (or mental short cuts) to find good enough solutions. Gigerenzer (2004) states that heuristics are:

- Simple relative to human capacities, allow fast and frugal judgements, can be easily understood and taught to a novice and can be generalised to new situations.
- To some degree specific to particular environments and types of problems.

## The recognition heuristic

This heuristic builds on the human capacity for recognition, for example of faces, voices, names. It shows that when trying to judge between options, where one option is recognised and another is not, people will infer that the recognised option has the higher value. For example, American and German students were asked which city had the bigger population - San Diego or San Antonio (Goldstein and Gigerenzer, 2002). 100 per cent of German students answered correctly (San Diego – they chose the city whose name they recognised). Only two-thirds of Americans answered correctly – they had heard of both cities so had too much information. Similar results have been found for judgements about the excellence of colleges and sports teams. This heuristic is successful when recognition is strongly related to the criteria on which the choice is being made, and in these circumstances the 'less is

more' effect applies – that is, more knowledgeable groups make worse inferences than less knowledgeable groups.

## The social heuristic

The social heuristic uses human capacities for social learning and imitation. In brief, this heuristic is based on choosing what the majority of one's peers are choosing (for example, thinking of getting married when most others in one's social group do).

Emotional processes can also be key building blocks of social heuristics, the prime example being falling in love as a stopping rule in the search for a partner.

## Heuristics based on reasons

Another set of heuristics comes into operation when recognition is not a valid response or when people know too much to take such short cuts. People then search for cues or reasons for action. However often they do not go systematically through all cues and add and weight them. Rather, short cuts are taken to reach a decision based on one-reason decision-making ('Take the Best'), or adding up cues until a threshold is reached (the 'tallying heuristic'). Each of these strategies comprises i) a search rule; ii) a rule for stopping; and iii) decision-making.

For Take the Best the process involves: i) look up cues with the highest validity first; ii) if one object has a positive cue value and the other does not then stop the search. If not, exclude this cue and continue to search on the next most valid cue; iii) predict that the object with the positive cue value has a higher value on the criterion and therefore choose this option.

For the 'tallying heuristic' the strategy is: i) search through cues in random order and look up values for each cue, either all cues or a predefined number; ii) then stop the search and determine which cue has most positive values; iii) predict that the object with the highest number of positive cue values has the higher value on the criterion and therefore choose this option.

There are a considerable number of empirical studies that have looked at use of Take the Best, but there is comparatively little empirical work on tallying. One-reason ('Take the Best') decision-making has been observed in magistrates making bail decisions on the basis of one reason (Dhami, 2003); GPs prescribing lipid-lowering drugs (Dhami and Harries, 2001); and parents deciding which doctor to take their child to (Scott, 2002). However, this type of decision-making is not used by all participants in these studies. In a series of experimental studies, Newell and Shanks (2003) and Newell *et al.* (2003) found that only around 60 per cent of subjects adopted heuristics strategies, with around a third conforming to all three TTB rules. However, taking each rule separately, between 75 and 92 per cent of subjects adhered to TTB search, stop or decision rules. Newell *et al.*, found no effect of

complexity of task on whether or not TTB rules were used and suggest that personality factors may influence strategies used.

## Implications of heuristics for understanding decision-making

The implications to be drawn from heuristic models are that more information and more choice is not always better. There is considerable empirical evidence on this (for example, Schwartz, 2004); experts usually base their judgements on a few pieces of information (Shanteau, 1992), and shoppers buy more when there are fewer varieties (lyengar and Lepper, 2000).

A concept which can be seen to be related to use of heuristics is that of 'satisficing' as opposed to 'maximizing' (Simon 1957, 1982). Satisficing refers to satisfying ourselves while falling short of maximizing goal satisfaction. Heuristics are satisficing procedures for making inferences and decisions. Interestingly, satisficers have been found to be more optimistic and have higher life satisfaction than maximizers, who are more depressed and show more regret and self-blame (Schwartz *et al.*, 2002).

## Relevance of heuristics to Panel Study

Heuristics have been used to make decision trees, for instance in clinical decisionmaking (Green and Mehr, 1997; Fischer *et al.*, 2002). We might want to think about producing decision trees from analysis of the study data. In relation to choices about support services, the ideas put forward in fast and frugal heuristics can provide a basis for exploring the processes by which service users and carers make choices. What are the important cues they use? How much information do they have? How much information do they actually use in making the decision? What sort of information assumes greatest importance? In what circumstances do people use more or less information? What happens if the cues used by user and carer or by users and professionals are different?

## Making decisions involving risk or uncertainty: prospect theory

Most decisions involve risk and there is a substantial body of work on risky decisionmaking dating back to the 1920's. This has been inter-disciplinary, with economics and psychology as the key players. Other disciplines (business, law, medicine, political science and public policy) have applied the principles and models developed. As with other areas of decision-making research, two key questions have been addressed:

- How should individuals behave when faced with a risky choice (normative)?
- How *do* individuals behave when faced with a risky choice (descriptive)?

A further approach (prescriptive) is more recent and is concerned with how to get people to act more normatively. This area of work is called decision-analysis.

## **Risk and uncertainty**

Within scholarly work, a clear distinction has been made between risk and uncertainty (Knight, 1921). Risky decisions are those decisions where the probabilities of the various possible outcomes are objective or known (for example, gambling on the flip of a coin, a roulette wheel). Uncertainty occurs where the decision-maker has to estimate or infer the probabilities of the various outcomes happening (for example, placing a bet on a racehorse or the chances of the weather being sunny for a barbecue at the weekend). Most of the important decisions we make involve uncertainty rather than risk. Our understanding of decisions involving uncertainty is much less advanced than our understanding of risky decision-making. However, it is argued that models of risky decision-making can be extended to decision-making involving uncertainty and there is a sizeable body of research to support this argument (Wu *et al.*, 2004).

## **Prospect theory**

In 1979, two economists (Kahnemann and Tversky) published a paper 'Prospect Theory: an analysis of decision under risk'. This paper identified the inadequacies of previous descriptive models of risky decision-making (notably Expected Utility Theory (Friedmann and Savage, 1948; von Neumann and Morgenstern, 1947) and Subjective Expected Utility (Savage, 1954)). Prospect theory is acknowledged to be the best descriptive model of risky decision-making. Since 1979, Prospect Theory has been developed and modified, with two parallel streams of work going on: economists have been striving to refine the mathematics of the model, while psychologists have been more interested in exploring the underlying psychological processes (for example, cognitive processes, personality and motivational factors). This work (primarily the economic aspects) has resulted in an evolved form of the model known as Cumulative Prospect Theory (Tversky and Kahnemann, 1992). An important aspect of its development has been to incorporate decision-making involving uncertainty.

In essence, Prospect Theory is a mathematical model which predicts or explains decision-making. Fortunately it is not necessary to explain the mathematics in order to identify some key principles which are important to our understanding of decision-making in situations of uncertainty. These principles will now be described.

## How risky are we?

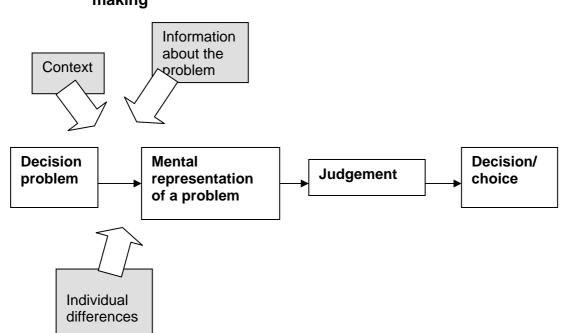
Before Prospect Theory it was assumed that people are risk averse – that is, they will always choose the least risky option. However, it is not as simple as that. In fact, we are both risk seeking *and* risk averse. The way in which the options (or attributes of options) under consideration are perceived (or presented) in terms of whether they are gains or losses is the primary influence on whether, in a particular situation, we

are risk seeking or risk averse. Key research findings with respect to risk-seeking and risk aversion are as follows:

- Losses 'loom larger' than corresponding gains. For example, for equal stakes, most people often won't bet on a coin toss.
- People will take greater risks to avoid loss than they will to achieve a gain.
- Gains and losses are not (necessarily) absolute but also include changes to the existing state. So a loss of £100 is more serious for someone with £200 in their pocket compared to £1000 in their pocket.
- People are averse to sacrificing a certainty for the chance of getting a slightly better outcome.
- Loss aversion means that people favour the status quo over other options. A simple example here is an experiment by Knetsch (1989). In this study students were randomly given a gift of either a mug or a bar of chocolate and then allowed to trade. One might have expected a considerable amount of trading given that the gifts were free and randomly assigned. However, around 90 per cent of students chose not to trade and kept the gift they were given.
- People will pay a large premium to avoid the small chance of receiving nothing (for example, insurance).
- Options (or the attributes of options) are evaluated as losses or gains relative to a point/points of reference. These points of reference reflect the nature of the choice to be made. So, a person with a limited income going about choosing a car might use fuel economy and purchase cost as points of reference. (Other points of reference might also creep in, such as the 'look' of the car, and personal views about a particular type, for example, petrol versus diesel).
- Points of reference which are relevant to a decision are based on individual beliefs and values which are salient/relevant to the particular decision. So, going back to the car example, environment-friendly credentials might be the key reference point for one person while 'pose value' will be the key reference point for another.
- It is possible to manipulate the way information relevant to a decision is valued or perceived. A simple example is provided by Levin's work on people's choices of food. Levin (1987) showed that people change in the way they perceive a food according to whether the fat content is described in positive (for example, 90 per cent fat free) or negative (for example, 10 per cent fat) terms.

## Framing

A key finding from (or aspect of) the Prospect Theory approach is that, when faced with a decision problem, people form a mental representation of that problem (Figure 2).





(adapted from: Soman, 2004, p 380)

The mental model (or framing) of a problem includes both information about the decision problem and the context of the decision problem (for example, time constraints, emotional aspects etc.). Individual differences in the way information is perceived, organised and interpreted, and differences in context, mean that the decision or choice made about the same decision problem will vary between individuals and across different contexts (Kahnemann and Tversky, 1984; Shoemaker and Russo, 2001). As Soman (2005) points out:

The implication of a personal and situation specific mental model is that two individuals who might be presented with the same problem stimulus *might actually be solving different 'mental' problems*. (p380: our emphasis)

Framing is a subconscious activity but can be manipulated deliberately by the individual making the decision or by other individuals, as has been extensively demonstrated in laboratory experiments (Kahnemann and Tversky, 1979; Tversky and Kahnemann, 1981). For example, researchers have shown that manipulation of the way outcomes are described (in terms of loss or gain) results in completely different decisions being made. What is also interesting is that in these experiments subjects did not try to reframe the information given to them. Even the researchers conducting these experiments found the strength of the 'framing effect' striking: 'We were surprised by how easy it was to construct different versions of a decision problem that were transparently equivalent when considered together but evoked different preferences when considered separately' (Kahnemann, 2000). The notion

that the way that decision-related information is perceived and processed is critical to decision-making points us to the information processing models of decision-making described above.

#### **Further loss aversion effects**

There are other ways in which our aversion to loss has been shown to affect decision-making. These include:

## The sunk-cost effect

It has been shown that the greater the price paid for a product, the more likely people are to use or consume it, even in the face of risk or adversity (Arkes and Blumer, 1985). Thaler (1980) gives the following example: 'A man joins a tennis club and pays \$300 yearly membership fee. After two weeks of playing he develops a tennis elbow. He continues to play (in pain) saying 'I don't want to waste the \$300!''. Here the loss of a past investment drives the decision to continue to play despite considerable pain.

## Advantages and disadvantages in choice

Researchers have shown that the extent of difference between two options will be viewed as greater if framed as a difference between two disadvantages, compared to a difference between two advantages. Thus the way information about options or attributes of options (as advantages versus disadvantages, or losses versus gains with respect to a reference point) is presented will affect the decision made.

## A reluctance to choose

This is observed in situations where someone is having to make a choice between two options. One of these options is better with respect to one attribute while the other option is better with respect to another attribute. As long as the person is still in the process of making the choice, they have not experienced a loss in terms of either attribute. Once an option is chosen, the person then experiences a loss. At this stage, the rejected option might start feeling more valuable and lead to regret about the decision made (Carmon, Wertenbroch and Zeelenberg, 2003). For example, for someone choosing a home two key attributes might be the number of bedrooms and being on a quiet street. One house (Option A) under consideration has 4 bedrooms but is on a street which is noisy during the rush hour periods, the other (Option B) only has 3 bedrooms but is quietly situated. By choosing Option A the person feels they have lost living on a quiet street and this might then become a more important attribute than the number of bedrooms and they then regret the decision to buy Option A.

#### How people structure decisions

Prospect theorists argue that people can both consider (and compare) all options at once or consider options sequentially (for example, Read *et al.*, 1999). This phenomenon appears similar to the different types of heuristics described in the information processing approach above.

#### Implications for the Panel Study

One of the key implications of Prospect Theory for the panel study is that it is possible (intentionally and unintentionally) to externally manipulate a person's decision by the way a decision problem is presented and associated information provided. This could happen in situations where a professional is presenting options/choices and also within close relationships (mother/child; partner/partner), where one of the individuals in the relationship holds more information relevant to the choice. It is important we explore and identify this as there are clear policy/practice implications.

In situations of joint-decision making, Prospect Theory argues that the same decision-problem might be being framed differently by the two people involved, either because they hold different values/attitudes or because the outcome will have different impacts on the two individuals involved (for example, a decision about moving an older person into residential care could be framed by the person to be moved as loss of independence, but by their partner as removal of a significant care burden or a way of improving the quality of care received). This would suggest that it is important for the Panel Study to ascertain people's representations of the decisions they are making (an ostensibly identical decision may well be framed differently by different people), and also to explore the information they are presented with.

In addition, framing effects might be an important phenomenon to explore in situations where people change their minds or choices have to be revisited due to changing circumstances; the choice problem may have been reframed, or values/attitudes revised as a result of changes in the condition or other circumstances.

Finally, Prospect Theory also provides a framework by which we can understand the seemingly 'irrational' decisions being made by participants.

# Decision-making: the relationships between attitudes and behaviour

## **Theory of Reasoned Action**

The Theory of Reasoned Action (TRA) (Ajzen and Fishbein, 1980) is particularly influential in the field of decision-making regarding health-related behaviour. It builds on theories regarding relationships between attitudes and behaviour. Its basic assumption is that in most cases individuals can choose whether or not to perform a behaviour. TRA states that the primary determinant of behaviour is the person's intention – given the appropriate opportunity to perform a behaviour, intentions will guide behaviour. Ajzen and Fishbein propose that intentions are derived from two cognitive processes: the person's attitude towards the behaviour and his/her perceived social norms regarding the behaviour – termed 'subjective norm'.

Attitude is assumed to be determined by the person's belief about, and evaluation of, the outcomes of an action. TRA recognises that behaviour occurs in the context of social influences which exert pressure to perform or not perform a particular behaviour. A further influence on intention is the subjective norm, which is a combination of the person's belief that people who are important to him/her think that s/he should or should not perform the behaviour, and the person's motivation to comply with these opinions.

## Theory of Planned Behaviour

TRA originally assumed that most behaviours of interest are those where the person has the resources, skills and opportunities to engage in their desired action. However, recognising that this is often not the case, Ajzen (1988) proposed an extension of TRA – the Theory of Planned Behaviour (TPB). This added a further dimension to TRA – that of perceived control over the intended behaviour. Perceived behavioural control is influenced by internal factors (skills, ability, information, emotions) and external factors (opportunity to engage in the behaviour and the extent to which performing the behaviour depends on the cooperation of others). A person's perceived behavioural control reflects his/her beliefs about factors that may inhibit or promote the performance of the behaviour. Perceived behavioural control is posited to have a causal influence on intentions, but actual behavioural control also has a direct influence on behaviour (see Figure 3 below).

Meta-analyses of studies applying TPB conclude that it accounts for considerable proportions of the variance in intentions across a range of behaviours (39-41 per cent) and a somewhat lower proportion of variance in behaviour (27-34 per cent) (Armitage and Connor, 2001; Godin and Kok, 1996 – cited in de Wit and Stroebe, 2004). TRA and TPB have been applied to a wide range of decisions about

behaviours (for example, dealing in stocks and shares, smoking initiation, shoplifting, condom use, oral contraception, participation in exercise).

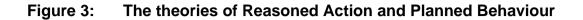
## **Relevance to Panel Study**

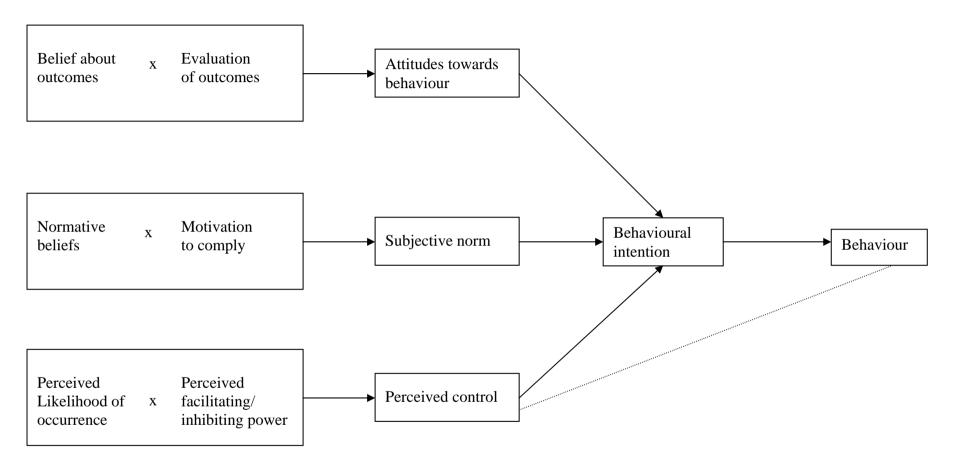
The components of these theories (TRA and TPB) have a number of implications for how we look at choice and decision making. The concept of subjective norm can be seen to have relevance to many instances of decision making where the attitudes of key people, such as relatives and professionals, and the importance users and carers attach to these, are likely to influence decisions. For instance, one study found that parents felt under pressure from family and/or health professionals to make a particular decision about gastrostomy for their child (Guerriere *et al.*, 2003). It will be important to explore in interviews who are the people who are important in any decision, what their attitudes towards the decision are or were and what weight users/carers placed on this. Similarly, we should explore people's beliefs about, and evaluations of, the outcomes of a chosen action and how these influence the choice made.

Research on adaptation in families with disabled or chronically ill children points to the importance of family values and beliefs in adaptation and resilience (for example, Summers *et al.*, 1989). There is also evidence that having a disabled child can spur parents to examine their own beliefs and their assumptions about their social environment. In a small qualitative study of parents of children with Down's syndrome or an autistic spectrum disorder, King *et al.* (2006) found that parents became more aware of their beliefs. They felt that it was important to be clear about their values because these affected their priorities for the child, and thus the supports and opportunities they provided and sought for the child and the goals they worked towards. As this quote from a parent illustrates, these values play a key role in seeking and making choices:

I think that, as a family with a child who has a disability, we have to be very clear on priorities because often we have to present those priorities . . . to professionals, to teachers, but sometimes even to family members and neighbours because we are often challenged on what those priorities are. . . . Often people don't accept the fact that we know best, so we have to be very clear about those priorities and, even though they change at times, we have to make those decisions. And if we don't make those decisions, we don't have clear choices for our children, for our families. Then we are just sort of nudged into what is out there and the world is taking control really. If we don't put our priorities straight then we don't get real choices.

(King et al., 2006. p.359)





From Bennett and Murphy (1997)

The study also suggests that these families may be clearer about their beliefs and priorities than families with non-disabled children, as they are called on to articulate them more often to justify decisions. This indicates that it will be important in the Panel Study to examine individuals' beliefs, values and priorities and how these affect choice making; how such beliefs may have changed and continue to change with changes in the adult or young person's condition; and how these changes impact on choices. In particular, TRA and TPB point to the importance of exploring the effects when changes in beliefs are in an opposite direction to normative social influences. Research on families with disabled/chronically ill children points to a number of ways in which families' re-evaluation of values may result in a devaluing of some common social values, such as achievement, material values and income (for example, King *et al.*, 2006; Sloper, 1996).

The issue of perceived control is also clearly important in the decisions users and carers make. For example, parents' and young people's perceptions of their abilities to deal with the technology of gastrostomies or assisted ventilation will influence their decision about instituting this technology (Miller *et al.*, 1990).

# Section 3: Factors Which Affect Choice or Decision-Making

## **Emotion and choice**

Choice making has both cognitive and emotional components. At a general level, emotion and cognition are both types of information processing, but they have different functions. Many theorists see emotion as alerting individuals to important features of a situation and providing direction for cognitive processes and behaviour (Lemerise and Arsenio, 2000). In relation to choice, people think about the options and the likely consequences of choosing an option, but in addition there are strong emotional factors in play. People have feelings about the decision and expectations about feelings that might result from choosing different options. (The emotions actually experienced as a result of the outcome of a choice may or may not concur with earlier expectations). These emotions help to prioritise between different options and reduce the amount of information to be processed. It has been argued that emotions are particularly likely to play a role in conditions of uncertainty and incomplete knowledge which characterise many decisions, as they reduce information processing (Lemerise and Arsenio, 2000). Affective reactions are often the first reactions to stimuli and may then guide processing and judgement; in some cases individuals may choose things they find attractive and then justify choices with reasons (Zajonc, 1980). The mechanisms by which emotion informs choice are known as 'somatic markers'; for example when a negative outcome becomes linked with a specific thought or behaviour, a negative 'somatic' or gut feeling is experienced which adaptively can protect against future losses and narrow down the field of alternatives to choose from. This mechanism is usually adaptive, but can produce bias which is maladaptive (Damasio, 1994).

Evidence for the centrality of emotion in decision making is provided by studies of people with neurological damage which interferes with the processing of emotional signals but not basic cognitive functions. Such damage leads to impairments in decision-making processes (Behara, 2004). An extensive and growing body of research has examined the effects of emotion, affect and mood on information processing, judgement and decision-making<sup>1</sup>. Some studies have focused on 'integral' affect, that is feelings experienced about a particular stimulus (or choice), whilst others seek to understand the influence on decision-making of 'incidental'

<sup>&</sup>lt;sup>1</sup> Generally 'affect' refers to traits which are pervasive and broad and have longer duration, such as good or bad feelings, 'emotions' are narrower and refer to particular states (for example, anger, fear, happiness). The term 'mood' refers to a feeling that is low in intensity but has no specific object (Finucane *et al.*, 2003). Sometimes the terms affect or emotion are used to encompass all these states.

affect, that is feelings such as mood states that are independent of the stimulus but can influence the decision process.

## The role of affect in decision-making

Peters *et al.* (2006) argue that both integrated and incidental affect have four different roles in judgement and decision-making:

- Affect can act as information feelings about a choice are information that guides decision-making and can shape the value of an alternative. These feelings can be based on prior experiences or thoughts relevant to the choice option and/or can be the result of a less relevant current state of emotion or mood. Schwartz (2000) also notes that individuals are more likely to recall information from memory that is congruent with their current feelings. Thus feelings influence the information brought to bear on the decision.
- By translating more complex thoughts into simpler affective evaluations of choice options, people can compare good and bad feelings rather than attempting to integrate a mass of conflicting logical reasons in more complex decisions. Thus affective information may be more easily integrated into judgements than non-affective information and act as a heuristic. Emotional processes are faster than cognitive processes, so if an individual is under increased pressure of time to make a choice, affect may have greater influence than cognitive processes (Svenson, 2003). However, mood also influences estimates of the outcome of a choice (Schwartz, 2000). Happy mood results in overestimating the likelihood of positive outcomes and underestimating the likelihood of negative outcomes and sad mood has the opposite effect. In this way, affect may influence evaluations of all alternatives (Svenson, 2003).
- Affect can act as a 'spotlight' the extent or type of affective feelings focuses the decision maker on new information and this new information is used to guide the judgement.
- Affect can be a motivator of information processing and behaviour. Affect is linked to approach and avoidance behaviour; moreover, people tend to act to maintain or attain positive mood states.

Finucane *et al.* (2003) put forward the Affect Heuristic theory, based on existing empirical evidence on affect and decision-making. This suggests that positive and negative feelings become attached to 'images'<sup>2</sup> through learning. The pool of affective feelings related to particular 'images' then serves as a cue for judgement

<sup>&</sup>lt;sup>2</sup> 'Images' are defined as sounds, smells, visual impressions, ideas, words to which positive and negative feelings have been attached through learning.

and decision-making. Using an affective impression can be easier and more efficient than weighing up the pros and cons of various choices and thus can form a mental short cut or heuristic, which guides reason and assigns priorities between goals.

Svenson (2003) posits the Diff Con Theory, based on the observation that a 'decision maker must find or create an alternative that is sufficiently superior to its competitor(s)' (p.290). Differentiation is the process by which a superior alternative is identified and involves evaluation of the alternatives and changes in the representation of the decision problem to increase the distance between alternatives. Consolidation maintains this differentiation post-decision and protects against regrets. Within this theory, both affect and cognitive processes are involved. Affect influences both the way information is processed and the attractiveness of the information. In addition, decision problems can also influence affect, for example having to decide between a set of bad alternatives can induce negative mood.

Incidental affect is also linked to the extent of processing in decision-making. Investigations of incidental affect have generally found that people engage in more systematic processing when in negative emotional states or moods, whereas people in positive states or moods engage in more heuristic processing (Tiedens and Linton, 2001).

## Emotion-specific influences on decision-making

A number of writers have moved beyond investigation of valence (positive or negative feelings), which suggests that all positive affect would lead to optimistic judgements whereas all negative affect would lead to pessimistic judgements, to look at emotion-specific influences on judgement and choice. Studies have found differential effects for specific emotions. Lerner and Keltner (2000) found that the negative emotions of fear and anger have different influences on judgement. They found that fearful people made higher risk assessments, whereas angry people made lower risk assessments. Other studies have found that sadness promotes systematic processing, whereas anger encourages heuristic processing (Bodenhausen, 1993; Lerner *at al.*, 1998). Lerner and Tiedens (2006) reviewed research on the impact of anger on judgement and decision-making, concluding that anger has specific impacts leading to selective processing of information, increased risk-taking and optimism.

Tiedens and Linton (2001) suggest that the effects of specific emotions on processing are related to the certainty appraisal of these emotions. Studies of emotion-appraisal associations show that specific emotions are reliably associated with particular sets of appraisals, for example anger is associated with unpleasant situations but certainty about what is happening; in contrast fear is also associated with unpleasantness but with uncertainty about what has happened or will happen. These patterns are consistent across a range of populations and using a range of

research methods. Tiedens and Linton concentrate on certainty and uncertainty – anger, disgust, happiness, contentment are associated with certainty; hope, surprise, fear, worry and, to an extent, sadness are associated with uncertainty. Empirical work by Tiedens and Linton suggests that in decision-making, certainty-associated emotions result in less substantive and more heuristic processing, whereas uncertainty-associated emotions produce more thorough processing.

Lerner and Keltner (2000) explored both the certainty/uncertainty and individual control/lack of control appraisals associated with specific emotions and suggested that these influence judgements of risk, as they are 'cognitive metafactors' identified in the risk literature as reliably determining risk assessment. These metafactors are the level of 'unknown risk' – defined at its highest level as hazards judged to be uncertain; and level of 'dread risk', defined at its highest level as perceived lack of individual control (for example, McDaniels et al., 1997; Slovic, 1987). Fear involves appraisals of low certainty and low individual control whereas anger involves appraisals of high certainty and high individual control. If these appraisal tendencies influence judgement, then fear should lead to pessimistic risk assessments and anger should lead to optimistic risk assessments. On the other hand if valence is more important, both fear and anger would lead to pessimistic assessments. Lerner and Keltner's (2000) study of 97 students found, as noted above, that fearful people made higher risk assessments whereas angry people made lower risk assessments. Their measures related to dispositional fear and anger, but they also found that dispositional emotions predicted current state (momentary) emotions. They suggest that the effects of dispositional emotions and momentary emotions will be similar but may differ in magnitude, with dispositional emotions having greater effects. This is likely because momentary emotions are likely to be consciously linked to a specific cause and this should reduce the effect on judgements of other events. In contrast, dispositions emerge early in life; remain stable over the life course (Helson and Klohnen, 1998); are reflected in stable differences in underlying neurochemical systems (Davidson, 1998); and are thought to focus as ongoing schemas for organising and interpreting events (for example, Gasper and Clore, 1998).

An emotion that has received a considerable amount of attention in decision-making research is regret. Connolly and Reb (2005) identify three types of regret:

- Outcome regret the target of regret is the outcome of the decision;
- Option regret the target of regret is the option chosen;
- Process regret here the target is the way in which the decision was made (for example, too hasty, ill-informed).

Decision Justification Theory (Connolly and Zeelenberg, 2002) posits two components of decision-related regret: one associated with evaluation of the outcome of the decision, the other with self-blame for having made a poor (that is, unjustified) choice. These two components do not necessarily occur together – an

individual can regret an outcome but feel that the decision process was justified, or alternatively a good outcome can result from a poor decision. A number of empirical studies illustrate this. For example, Clark *et al.* (2001) found that among men treated for metastatic prostate cancer, those who expressed more regret about treatment decisions were more dissatisfied with the decision-making process; they thought they had received less information and were more likely to feel that they did not have much of a choice.

Early studies (for example, Kahnemann and Tversky, 1982) indicated that a bad outcome resulting from action seemed to engender more regret than the same bad outcome resulting from inaction. However, findings on concurrent regret have been contradictory. There is some evidence that people may regret inactions more than actions in the short term, and this pattern was also shown in a series of studies looking at real life retrospective regrets. In these circumstances, people tended to recall more omissions than commissions, the opportunities they had passed up rather than the actions they had taken (Gilovich and Medvec, 1995).

Lerner and Keltner (2000) suggest that there are boundaries to the influence of emotion on judgement and choice and that people do make judgements independent of their emotions in certain conditions. It is suggested that emotion-related appraisals are automatic (for example, Lazarus, 1991) but are deactivated when individuals become aware of their own judgement process, so conscious monitoring leads them to focus on judgement-relevant information and downplay emotion. Several studies support this – in particular, when people expected to be accountable for their judgements, they examined the relevance of cues more carefully and current feelings became less important (Lerner and Tetlock, 1999; Lerner *et al.*, 1998).

## The role of anticipated emotion

There is also evidence that decisions are influenced by anticipation of regret (Zeelenberg, 1999). However, a number of studies suggest that people's ability to predict future emotional states, including regret, is often poor. It is likely that in temporally extended sequences of decisions, complex interactions will occur between anticipated regret that influenced earlier decisions, experience of actual regret resulting from these decisions, and anticipation of regret during subsequent decisions. It is therefore important to explore decision makers' predictions of regret before making a choice and before the outcomes of that choice are known, as well as experienced regret after the consequences of the choice are apparent. It is also important to distinguish between process, option and outcome regret.

Empirical research also indicates that subjects asked to think about the regret they might experience after making a choice predominantly choose the safest option over a potentially better but more risky option – it appears that thinking about regret leads people to look for justifications for their choice (Simonson, 1992). In general people

are regret-averse and in many cases this results in risk-averse choices. However, research also shows that anticipated regret may result in risk-seeking tendencies in certain circumstances which relate to the likelihood of feedback on the different options; that is, when there will always be feedback on the riskier option but only on the safer option if chosen. This means that if choosing the safer option, the individual risks finding out that the riskier option was better, but not vice versa (for example, lotteries). Overall therefore, research shows that people are motivated to make choices that protect them from post-decision feedback which will lead to regret about foregone choices. Anticipated regret also seems to promote decision-aversion, that is, a tendency to delay or avoid decisions (for example, Beattie *et al.*, 1994).

Although anticipated regret has received the most attention in the literature as an influence on choice, other emotions may play similar roles. Mellers *et al.* (1999) suggest that people will choose the option with the greater subjective expected pleasure, and Connolly and Butler (2006) found that a number of anticipated emotions (regret, disappointment, rejoicing and elation) about the outcomes of choice guide choice and predict choice behaviour. However, they also found that these specific emotions did not predict choice more than general clusters of positive and negative emotions.

## **Decision-generated emotion**

It will be apparent from the discussion above that decisions can often be stressful and therefore people need to deal with decision-generated negative emotion. A decision situation presumes the existence of more than one, and often multiple, options and there is therefore a need for trade-offs prioritising some goal(s) over others. Luce (2005) puts forward a model of Emotional Trade-off Difficulty (ETD), highlighting that two important coping motivations often co-exist. These are motivation to work harder to successfully solve the choice problem and identify the best option; and motivation to avoid particularly distressing decision operations, such as explicit trade-offs between attributes. The ETD model proposes that this tension is resolved by:

- Making trade-offs implicitly rather than explicitly; focusing on only one, or a subset of, attribute(s); and not addressing between-attribute trade-offs.
- Preferring choices that are recommended by reasons independent of the characteristics of the alternatives, for example, focusing on a doctor's recommendation.

Efforts to cope with negative emotion in decision-making can thus affect the decision-making process.

The ETD model has particular relevance to decisions regarding health conditions, which are often characterised by difficult trade-offs. Efforts to minimise negative emotion may result in avoidance of such trade-offs regardless of available

information. Indeed the provision of information relevant to trade-offs or the explicit ceding of control over decisions to the patient may increase decision-related negative emotion. This has implications for policies on patient involvement, choice and control because where positive outcomes are not certain, patient control over a decision may heighten stress by reducing the individual's ability to cope by avoiding decision trade-offs (Folkman, 1984). In addition, the key role of emotion in decision-making suggests that patients/service users would benefit from emotional as well as informational decision support. Work on the information needs of children and young people with chronic conditions and parents with disabled children (Beresford and Sloper, 2003; Mitchell and Sloper, 2001) indicates the importance of such support in using information.

#### Emotion in temporally extended choice

Temporally extended choice refers to choices that must be made repeatedly and have consequences that change depending on what is chosen at each point. In this situation, what is best at one point can be in conflict with what is best overall. People often act as if choices only had immediate effects, but optimal choice in these circumstances requires combining options across time to achieve the best overall outcome. Much decision-making involves temporally extended choice – for example, avoiding back pain requires many choices relating to physiotherapy exercises and lifting behaviour to be made over time. In any one situation, the immediate choice may be to carry out a task such as lifting a cared-for person, which may be of no obvious immediate consequence; but the cumulative effects of such choices can be very costly. Different processes may be involved in these situations. A motivational dilemma may involve weighing the short-term and long-term alternatives; on the other hand, many temporally extended choice situations may not involve high level decision-making processes or even be perceived as choices.

Gray (1999) hypothesised that threat-related negative emotional states, including stress, result in a bias to choose the alternatives that are most advantageous in the short-term, even if those choices incur long-term costs. Empirical studies with students supported his hypothesis, indicating that negative emotions (both task-related and more general emotions) biased people towards favouring immediate consequences, despite costs to longer-term goals. Gray suggested that this may be an effect of framing, depletion of cognitive resources or narrowing of attention, or a combination of these factors. A framing account suggests that in negative emotional states people frame a series of choices as an unrelated series of items, rather than seeing the bigger picture. A cognitive resource account suggests that cognitive load from the emotional state could disrupt implicit learning about the temporally extended contingencies. Focusing of attention often occurs in emotionally arousing situations, suggesting that this may also be a factor affecting narrowing of temporal attention.

#### Individual differences in emotionality and effects on decision-making

People differ in both their emotionality (that is, the intensity with which they experience and express emotions) and their ability to regulate their emotions, and these differences are related to the development of social competence (for example, Eisenberg *et al.*, 1997). It is suggested that children who are high in emotionality and poor at regulating emotion will show deficits in social information processing (Lemerise and Arsenio, 2000) and this then affects judgement and choice.

#### Implications for the Panel Study

Clearly decision-making is strongly influenced by emotional factors. Some of the issues that will be important to be aware of and/or explore are:

- The feelings individuals attach to different choice options and the role of past experience in this, for example it is often suggested that parents' own experience of school affects their choices of school for their children.
- The decision maker's mood at the time of making choices this is likely to influence both information processing and the way in which options are viewed – particularly in relation to perceived risks and optimism\pessimism about options.
- The role of regret both about the outcome of a decision and the process by which the decision was made. It will be important to explore this over time. How does regret about an earlier decision influence a later decision?
- There is considerable potential for anticipated emotions, particularly anticipated regret but also anticipated pleasure, in the situations of choice that we will be looking at. We might explore how people's judgements of how different options would make them feel influenced the choices they made. Also how did this affect the decision-making process itself; for example, in situations where anticipated regret is high, does this lead people to delay/avoid decisions?
- The process of decision-making can itself be stressful. Do people experience stress by having to make choices? Does this lead to a narrowed focus on option attributes and more reliance on professionals' judgement? What are the longer-term consequences of this? How does this affect what choices people do/do not want to make? A key factor may be what emotional support people receive when making the decision. Who provides this? Do professionals see this as part of their role?
- Many situations we look at may be ones of temporally extended choices. How do people think about these choices? How do they balance short-term and longer-term considerations? Do they treat each choice as if it would only have immediate effects or do they consider the longer-term effects? How do current emotions, particularly stress, influence this? What are the characteristics/ situations of those who take the longer-term or short-term view?

- Individual differences in emotionality are likely to influence choices. We need to be aware of this but we can't directly investigate it in the study.
- The finding that conscious monitoring of decision-making leads people to focus more on information and downplay emotion has considerable implications for the study. Will being involved in the study lead people to focus more consciously on their decision-making processes? How do we avoid this? Can we avoid it or do we just accept and acknowledge the possibility of contamination of the sample? If we can't avoid it, how do we monitor it?

## Individual differences and choice/decision-making

#### Personality and choice/decision-making

Whilst it is acknowledged that personality factors will affect choice-making, this is not an area which has been *systematically* examined. Personality research is a vast and disparate literature with numerous models and theories and, similar to the decisionmaking literature, there is no over-arching model or set of principles. As a result there are discrete pockets of research which have looked one particular facet of personality (for example, locus of control, risk taking) and its impact on decisionmaking; or have approached the issue from a particular theoretical standpoint (for example, trait theory).

However, drawing both on theories of choice and decision-making and our understanding of personality, it is possible to draw up some general principles about the way personality will affect choice-making. What is clear is that personality factors influence all aspects of the choice-making process, including:

- The way a situation/problem is perceived;
- The extent to which a person wants to take control of making a decision;
- The extent to which a person uses/seeks out information;
- The desire to involve others in the decision-making process;
- The person's preferred decision-making style;
- The type of decision they made;
- The extent to which a person feels the need to justify their decision to others.

Different personality theories have alternative views on the way that personality factors will interact and affect these various stages and processes. In addition, there is a further body of research looking at the impact of personality on the development of beliefs, attitudes and coping styles, all of which have been implicated in theories of decision-making.

#### Implications for the Panel Study

It is important to bear in mind that differences in personality are likely to impact on joint-decision-making situations. There is clearly potential for differences in

personality to interfere and disrupt the shared decision-making processes, including expert and non-expert decision-making situations (Clack *et al.*, 2004). In addition, the effectiveness of professional support in decision-making would, to some extent, appear to be dependent on the extent to which that support is sensitive to, and can be tailored to, differences in personality. Finally, in relation to the groups represented in the panel study, it will be important to bear in mind the evidence on the adverse effect of the experience of disability on internal psychological factors such as self-efficacy, self-esteem and locus of control (for example, Hirst and Baldwin, 1986).

For this project it is important to be aware that factors such as personality influence the decision-making process. It will not be possible to explore this issue *per se* within the project, however.

#### Choice and cognitive capacity

The psychological theories of choice and decision-making described earlier highlight the fact that making choices can be highly costly in terms of the cognitive effort associated with gathering and then assessing and comparing information. Not unsurprisingly, therefore, within psychological research on choice/decision-making theory there is a body of work on the impact of 'cognitive capacity' on choice-making. This includes work on the effect of drugs (for example, opiates), personality disorders and other mental health problems, neurodegenerative disease, brain injury, ageing and learning disabilities on the decision-making process and decision-making efficacy. In addition, there has been work which has looked at 'softer' differences in cognitive capacity (such as numeracy skills) and their impact on performance in decision tasks. All this work is based on the notion that impairments of, or limitations in, cognitive capacity will impact on choice/decision-making ability.

In some cases the purpose of the research has been to shed further light on the cognitive processes underlying decision-making. Other research is more concerned with the way that impairments in cognitive capacity may affect people's ability to make choices about treatments or health care, their participation in research, and to manage everyday life decisions (for example, financial management). It is this notion of capacity that is reflected in the Mental Capacity Act (2005) and we explore this issue below on making decisions on behalf of someone else.

There is, in addition, a separate body of literature on the meaning of choice and the exercise of choice by disabled people (for example, Wre, 2004; Harris, 2003; Lancioni *et al.*, 1996). Within this literature there is some resistance to the emphasis on cognitive capacity as the sole indicator of a person's ability to take decisions. It is argued that social and environmental factors also have significant roles to play in developing decision-making skills and facilitating and supporting decision-making among people with learning difficulties (for example, Suto *et al.*, 2005; Harris, 2003). This is also reflected in the Mental Capacity Act, with its emphasis on provision of

support and information in appropriate and simple forms; and its recognition that decision-making capacity should be assessed for particular decisions, and not seen as a general characteristic of the individual.

In the following sections we review the findings from research on the impact of specific impairments in cognitive capacity on decision-making processes. A lot of this research has been carried out on specific populations or on particular conditions. We have endeavoured from this to extract key, over-arching issues.

#### Cognitive ability

In laboratory experiments, general measures of cognitive ability have been found to be associated with decision-making performance, with performance being adversely affected with increasing decision task complexity (for example, Gonzalez *et al.*, 2005). There is a body of more applied research which has shown that impaired cognitive abilities (for example, as a result of learning difficulties, ageing) affect decision-making abilities in general. This research is based on, as opposed to testing, the assumption that decision-making is a complex and cognitively demanding activity which requires certain cognitive skills and capacities. Such work does not tend, however, to explore the ways different aspects of the decision-making processes are or may be affected by impaired cognitive ability(ies).

#### Memory

Impairments in memory, particularly working memory, have been found to affect decision-making capacity (Stroup *et al.*, 2005). Working memory refers to the structures and processes used for temporarily storing and manipulating information. Other researchers have found that the decision-making strategies used, and the extent to which individuals are able to shift to more effective strategies, are related to working memory capacity.

#### Numeracy

Research suggests that numeracy *per se* (as opposed to being used as an indicator of general intelligence) is an important factor in decision-making (Peters *et al.*, 2006). Numeracy skills have been found to influence the types of decision strategies used to compare different options and, overall, this is thought to be beneficial.

#### The pre-frontal region of the brain

The pre-frontal region of the brain is the area of the brain which supports reasoning and decision-making. In the absence of any other cognitive impairment, damage to this region (through, for example, traumatic brain injury, neurodegenerative disease) has been found to affect decision-making ability (Denburg *et al.*, 2005; Fellows and Farah, 2005; Brand *et al.*, 2004; Fellows., 2004; Stout *et al.*, 2001).

# Choice and decision making by people with severe and profound developmental disabilities

In 1996, Lanciono et al. published a review of evidence on choice research with people with severe and profound developmental disabilities. It should be emphasised that the research they identified was concerned with experiments which explored choice and preferences in relation to familiar and concrete objects and/or activities. With respect to these, Lanciono et al. concluded that, when presented in an accessible way, most people with severe or profound developmental disabilities can make choices and express preferences about food and drink items, types of stimulation (for example, music, rocking) and activities. Laciono et al's. review also highlighted the importance of the environment and access to technologies to facilitate the expression of choice or preference. Developing the ability to make these sorts of choices may require practice. It may also demand specific skills on the part of professionals and/or family members in order to understand both an individual's possibly idiosyncratic way of communication and the context in which a communication behaviour is observed. As Ware (2004) observes, sometimes a behaviour indicating a preference will be observed (for example, a smile, relaxation of muscles) but it will not have been *intentionally* communicated by the person.

What is significant here is that none of the evidence reviewed by Lanciono *et al.* (1996) or subsequent research (for example, Schepis *et al.*, 1996) has concerned choices between events which will be on-going (that is, where a choice fixes what will happen next week or month) or future events (Ware, 2004). Such choices or decisions, Ware notes, require a 'relatively advanced level of cognitive development' (p.177) and cannot be made by people with severe and profound developmental disabilities. Ware concludes:

This is not to suggest that the task of trying to ascertain the views of people with profound and multiple learning disabilities should be abandoned. Rather we need to be realistic about the extent to which it is possible to ascertain the views of those with the most complex needs about complex issues. We need, on the one hand, to see the task of enabling someone to express their views as a learning/teaching task which may be very long-term, and on the other, when major decisions need to be taken about their future, we need to work out how best to take account of their likes, dislikes, strengths and needs. (p.178)

Clearly, proxies need to be involved in these situations. However, evidence suggests the use of proxies is not without its own issues. Cummins' (2002) review of research which has looked at proxies' abilities to judge the well-being of people with learning difficulties concluded that proxies with the closest relationships with the individual are the most reliable proxies; however, their own values and attitudes bias the inferences they draw. Additionally, the use of proxies is most likely to be problematic

in situations where the individual has extremely limited communication. The issue of proxies (or surrogate decision-makers) is discussed further below.

#### Implications for the Panel Study

The brief overview provided above reiterates the fact that making complex decisions is cognitively demanding. There may be instances in the 'sudden onset' group that we recruit people who have experienced an abrupt and significant change in their cognitive abilities and who are now struggling to make decisions or who are being excluded, or only peripherally included, in decision-making. It will also be interesting to explore/describe the strategies professional and family members use to support decision-making by those with cognitive impairments.

In terms of individuals with severe or profound learning difficulties or substantial cognitive impairment following brain trauma, questions need to be addressed about whether, how, and the rationale of, including these individuals in this project. Furthermore, if the decision is taken to include them then the issues explored with the carers/professionals involved may need to be modified to explore issues such as feelings and experiences of acting as proxies; confidence in understanding what the individual is communicating; and beliefs about the individual's choice- or decision-making capacities. These questions are explored further in the next section.

# Section 4: Specific Decision-Making Situations

### Making decisions on behalf of someone else

Literature on decision-making on behalf of another person centres around 'proxy' or 'surrogate' decision makers<sup>3</sup> and parents making decisions on behalf of their children. The situation is different for each of these groups. As far as surrogates are concerned, their role is to make a decision on behalf of someone who lacks capacity to do this themselves. They may be relatives, friends, carers or professionals, and may or may not have been designated by the person concerned as their surrogate. Much of the literature focuses on consent to health care treatment, including end-oflife decision-making. A key issue is establishing capacity and there are legal standards on consent capacity (see below). In contrast, parents already have legal responsibility for making decisions on behalf of their children (under 16 years). However, the role of children and young people in decision-making is increasingly being recognised and promoted. The United Nations Convention on the Rights of the Child (1989) Article 12 emphasises children's rights to express their views on matters that affect them and to have these views given 'due weight'. In addition, the National Service Framework for Children, Young People and Maternity Services states that services are required to 'give children, young people and their parents increased information, power and choice over the support and treatment they receive, and involve them in planning their care and services' (DH/DfES, 2004: p.9). Whilst it is by no means universal that children are consulted when decisions are made on their behalf, children's participation is becoming more common (Cavet and Sloper, 2004a). Nevertheless, disabled children are less likely to be involved in decisions than their non-disabled peers (Cavet and Sloper, 2004b). In addition, with the presumption of parental responsibility, less attention is focused on establishing a child's capacity than is the case for adults.

#### Capacity and the law

In England, the most recent legislation dealing with decision-making capacity is the Mental Capacity Act 2005. This states key principles:

A person must be assumed to have capacity unless it is established that he lacks capacity.

A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

<sup>&</sup>lt;sup>3</sup> These terms appear to be used interchangeably but surrogate is slightly more common, and will be used in this document.

A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

The Act also defines the meaning of lacking capacity:

For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.

It does not matter whether the impairment or disturbance is permanent or temporary.

A lack of capacity cannot be established merely by reference to:

- (a) a person's age or appearance, or
- (b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about his capacity.

The Act specifically excludes people under 16.

In deciding how to establish whether a person is unable to make decision for him/herself, the Act states that lack of capacity should be decided 'on the balance of probabilities' and sets out the following criteria. The person should be unable to:

- Understand the information relevant to the decision;
- Retain the information;
- Use or weigh that information as part of the process of making the decision; or
- Communicate the decision (whether by talking, using sign language or any other means).

A person should not be regarded as unable to understand information if s/he is able to understand an explanation of it in a form appropriate to him/her (for example, simple language, visual aids etc). The fact that someone is only able to retain information relevant to a decision for a short period does not prevent him/her from being regarded as able to make the decision. Information relevant to a decision includes information about the foreseeable consequences of deciding one way or another or failing to make the decision.

These provisions are decision-specific – that is, what should be assessed is the person's capacity to take a particular decision at a particular time.

Legal scholars in the US identify similar standards for capacity (Allen and Shuster, 2002): the ability to communicate a choice; the ability to appreciate the

consequences of the choice; the ability to understand relevant information; and the ability to rationally manipulate the information and give reasons for one's choice. It is clear from the above that these standards focus on the process of decision-making rather than the final decision made. Indeed, whilst some authors add to these conditions that individuals also make the most reasonable choice (for example, Marson *et al.*, 1996), this is specifically excluded in the Mental Capacity Act. This focus on process highlights the importance of cognitive abilities. Whilst simple cognitive abilities may provide the capacity to state a choice, higher order abilities are needed to manipulate information, appreciate consequences and be able to give reasons for a choice (Allen and Shuster, 2002).

If lack of capacity is established, then someone else must make the decision on behalf of the individual. This must be done in the person's best interests and the Mental Capacity Act provides a checklist of factors to use in establishing best interests. This includes what the person's views would be – sometimes known as 'substituted judgement'. However, empirical research has shown that here are considerable difficulties with predicting what people's decisions might have been.

#### Research on surrogate decision-making

There have been a number of empirical studies on surrogate decision-making. These appear to be largely atheoretical and concentrate on assessing how accurately surrogates reflect their relatives' views. A systematic review (Shalowitz *et al.*, 2006) identified 16 eligible studies involving 2595 surrogate-patient pairs, and 19526 paired patient-surrogate responses, which provided empirical data on how accurately surrogates predict patients' treatment preferences. In these studies, which used 151 hypothetical scenarios, surrogates were instructed to make the treatment decision the patient would have made if able. The studies sampled a range of different populations; terminally ill, outpatients, chronic disease, women aged over 70. The review found that overall surrogates predicted patients' treatment preferences with 68 per cent accuracy (95 per cent Cl, 63-72). They were most accurate in scenarios involving patients' current health (79 per cent) and use of antibiotics (72 per cent), and least accurate in scenarios involving dementia (58 per cent) and stroke (58 per cent).

The review also looked at results from two types of interventions to improve surrogate decision-making. Five studies compared asking patients to designate their own surrogate versus assigning surrogates based on a legal hierarchy. Two further studies asked patients to discuss their values and treatment preferences with potential surrogates. There was no difference in accuracy between patientdesignated surrogates and legally assigned surrogates, and the surrogate's relationship with the patient was not significantly related to accuracy. Of the two studies assessing the impact of discussion of patients' treatment preferences, one found no difference and the other found a slight but significant worsening of surrogate accuracy after discussion.

Despite these somewhat negative results, four studies included in Shalowitz *et al*'s (2006) review found that surrogates predict patients' preferences more accurately than physicians.

These findings are not surprising as, in general, social psychological research indicates that people overestimate the extent to which their own opinions and choices are shared by others – they 'project' their own characteristics on to others. Similarly, Fagerlin *et al.* (2001) found that sons' and daughters' predictions more closely resembled their own preferences than those of their parents, as did those of surrogates chosen by adults aged 65+. However these 'projective' predictions were not less accurate than counter projective predictions. In the absence of other information, projection can be a reasonable strategy and may operate as a judgement heuristic.

The literature focuses mainly, but not wholly, on surrogates' predictions in life-saving situations, so may not reflect accuracy in non-life-saving situations. All the studies used hypothetical scenarios and it is not clear what impact this has on accuracy. The fact that greatest accuracy was achieved in scenarios about current health may suggest that surrogate decision-making would be more accurate in real life. On the other hand, the stress of real life situations may have the opposite effect. Decision-making may increase stress for surrogates when they are not confident about what the patient would have wanted or do not themselves fully understand the risks and benefits of treatment (Allen and Shuster, 2002). The difficulty of predicting patients' preferences is also highlighted by Hiltunen *et al*'s. (1999) study of end-of-life treatment decisions, which found that vacillation in decisions was common for both patients and surrogates.

We have not been able to find many studies on other factors that influence surrogate decision-making, although one study investigated ethnic differences in end-of-life decision making by proxies (Hopp and Duffy, 2000). The study interviewed 540 relatives about advanced care planning and end-of-life decisions for their family member who died. The study found that treatment decisions for white people were more likely to involve limiting care in some situations and withholding treatment before death, completing living wills and designating power of attorney for health care. Treatment decisions for black people were more likely to be based on the desire to provide all care possible to prolong life. These differences were significant even after controlling for socio-demographic factors.

#### Research on parent decision-making

There are a number of studies focusing on parents making decisions for and with their children, covering a range of decision-making scenarios. These studies are mainly descriptive and few are based on theoretical frameworks. Most studies focus on medical decisions: insertion of gastrostomy tubes (Guerriere *et al.*, 2003); surgery (leg lengthening - Daniel *et al.*, 2005, hand surgery - Bradbury *et al.*, 1994, cardiac transplantation - Higgins and Kayser-Jones, 1996); cancer treatment (Ruccione *et al.*, 1991; Hinds *et al.*, 1997); life-sustaining treatment (Kirschbaum, 1996); immunizations (Wroe *et al.*, 2004); psychotherapy (Gustafson *et al.*, 1994). A few focus on other situations, including choice of child care (Fulmer, 1997) and disclosure to a child of the child's HIV status (Lester *et al.*, 2002). They include qualitative, quantitative and multi-method studies. In contrast to the literature on surrogates, most of these studies focus on real life decision-making, although two (child care and psychotherapy decisions) used hypothetical situations.

Key factors identified as influencing parents' decision-making are:

• Parents' emotional response. This includes anxiety at the time; anticipated regret; and feelings of responsibility if harm occurs to the child as a result of the decision or if parents don't give the child a chance for treatment, even though the odds of success may be low (Daniel *et al.*, 2005; Wroe *et al.*, 2004; Guerriere *et al.*, 2003; Higgins and Kayser-Jones, 1996; Bradbury *et al.*, 1994; Ruccione *et al.*, 1991):

If we'd done it and failed, well, we'd have to live with that...but not to have tried at all, then I think we would have been failing her and ourselves'. (Bradbury *et al.*, 1994: p.24)

Anticipated regret also included the fear that the child would later criticise the parent for the decision they took (Bradbury *et al.*, 1994).

Interestingly, attitudes towards action versus inaction and anticipated regret were found to be important in Wroe *et al*'s. study of decisions regarding early childhood immunization. In this study 195 mothers completed questionnaires antenatally on perceptions of risk and benefits of immunization and then were contacted later (when the baby was 10 weeks old) about whether the child had been immunized. Non-immunizers had higher antenatal ratings of anticipated responsibility for harm that occurs following action and greater anticipated regret of that action. Immunizers had higher anticipated responsibility for harm that occurs following inaction and greater anticipated regret of that inaction. These emotional factors were better predictors of the likelihood of immunizing their child than perceptions of physical risks and benefits. The effects of emotion on information processing and recall are indicated by Ruccione *et al's.* (1991) finding that parents with higher levels of anxiety were more likely to believe that the risks of treatment for their child's cancer were not explained clearly.

- Responsibility as parents, both for the child concerned and for the rest of the family. Parents distinguished between their child's and their own interests and tried to balance the child's best interests with their own needs, as well as needs of other family members (Daniel *at al.*, 2005; Higgins and Kayser-Jones, 1996; Kirschbaum, 1996; Bradbury *et al.*, 1994). For example, in the case of life-sustaining treatment, parents wanted their child to have more time to experience life and they wanted more time for themselves with their child. However, this had to be balanced against the child's suffering and quality of life. When parents decided that this was not a life the child would wish for they sought to withdraw treatment (Kirschbaum, 1996). Parents also considered the anticipated effects on the family of their decisions about the care of their ill child (Kirschbaum, 1996).
- The child's involvement in decision-making. In the case of all but very young children (around age six), parents believed that their role was to help the child make the decision that was right for the child (Daniel *et al.*, 2005; Kirschbaum, 1996; Hinds *et al.*, 1997; Bradbury *et al.*, 1994). Similarly, in the case of disclosure to the child of HIV status (Lester *et al.*, 2002), children aged six and over had a key influence on parents' decision to disclose because of their questions and their ability to participate (or not) in treatments. Where parents were not able to involve the child in decision-making, they were concerned to respect the best interests of the child and to try to project what the child might want (Kirschbaum, 1996). As noted above, this included distinguished the child's own interests from their 'selfish needs' as parents.
- Information from and trust in professionals. The role of professionals in information provision is highlighted in a number of studies (Guerriere *et al.*, 2003; Hinds *et al.*, 1997; Higgins and Kayser-Jones, 1996; Bradbury *et al.*, 1994). In addition, needs for different kinds and sources of information are highlighted in Guerriere *et al's.* (2003) study of decisions about gastrostomy tube insertion. Twenty (out of 50) mothers in this study felt that they did not have an adequate amount of, and/or the right type of, information before making the decision. Information from other mothers whose children had had the procedure was lacking but felt to be potentially a valuable aid in decision making. Parents used information to inform them about the gains and losses that would be associated with the decision alternatives, but studies indicate that use of information is by no means straightforward. Studies show that parents include both reasons inconsistent with evidence-based information and

emotional reasons in their decision-making (Wroe *et al.*, 2004; Higgins and Kayser-Jones, 1996; Gustafson *et al.*, 1994) and that emotional factors were more important in the decision than informational factors. Kirschbaum (1996) suggests that parents' beliefs about spiritual/supernatural versus natural reasons for why their child had a life-threatening illness partly shaped whether their decision-making was guided mostly by faith and hope or by information seeking and mastery. In addition, trust in the person who provided the information and the quality of communication and interaction with the person providing the information was found to be more influential than the information itself (Hinds *et al.*, 1997; Bradbury *et al.*, 1994).

- Uncertainty about outcome is a key factor in the decisions studied and a small number of studies examined the effects of personal variables in decisionmaking strategies used by parents in these situations. Fulmer (1997) identified two major strategies in parents' decisions regarding child care (in a hypothetical situation). These strategies were:
  - a) 'compensatory' involves high levels of information processing in which the maximum amount of information is accessed; and weighing of alternatives against each other on all dimensions deemed relevant.
  - b) 'non-compensatory' involves reduced processing and less cognitive effort, accomplished by employing rules by which an alternative can be accepted or rejected quickly after only an incomplete search of its dimensions. There is no attempt to weigh an advantage on one dimension with a disadvantage on another. This strategy implies use of 'skilled omission' and is deemed to be more cognitively efficient (Ettenson *et al.*, 1987).

Fulmer found that parents with more years of formal education and higher levels of parental awareness (understanding of child behaviour, child development and their role as a parent) used less information (noncompensatory strategies) and more variable patterns in searching for information.

Ruccione *et al.* (1991), in a study of parents making decisions about consent to treatment for childhood cancer, found that parents with higher levels of education were more likely to think that risks had been explained clearly but also that they had not been given enough time to make the decision.

 Pressure from people or time. One study (Guerriere *et al.*, 2003) explored whether parents felt under pressure to make a particular decision. Half the parents in the study reported feeling pressure from health professionals and family members (12 reported pressure to refuse gastrostomy and 13 to agree). Another study (Fulmer, 1997) investigated the effects of time pressure on decision-making strategies but found no differences in strategies employed with and without time pressure and the personal factors influencing these.

Spontaneous v logical decision-making. Spontaneous decision-making has ٠ been defined as an instantaneous choice without a process of deliberation. One explanation of this is that it avoids pre-decision conflict. Higgins and Kayser-Jones (1996) found that five out of 15 parents making decisions about cardiac transplantation made spontaneous decisions (four chose transplant, one no treatment). The remaining 10 used logical decision-making behaviours (six chose transplant, three palliative surgical intervention and one no treatment). Logical decision makers preferred to have more autonomy and participation in decisions and spontaneous decision makers preferred less autonomy and wanted to be guided completely by the physician's recommendations. Kirschbaum (1996) suggests that the timing of decisions in relation to the course of the child's illness was important in the type of decision-making used. Early in the course of the illness, when there was urgency to decide, parents were likely to make a choice based on one key consideration - that the child should live - and did not deliberate when faced with giving consent to an intervention. When there was less urgency and they had time to consider alternatives, parents were more likely give weight to projected quality of life in their decision.

#### Implications for the Panel Study

The literature on parent and surrogate decision making highlights the need for us to clarify who we focus on in the panel study as this will influence sample selection criteria and interviewing strategies. There are three decision-making situations that could be included:

- The person making a decision for themselves.
- The person making a decision jointly with a parent(s) or carer(s).
- Surrogate(s) or parent(s) making a decision on behalf of a disabled person who lacks capacity to make the decision.

We will include the first two situations and the third may occur during the study if people's capacity changes. However, we can also include people who lack capacity at the recruitment stage. We should be aware that the sorts of choices we are looking at go beyond the simple capacity to state a choice and require higher order abilities to understand and process information and be able to reason and predict/ appreciate consequences. On this basis, there are a considerable number of young people (particularly those with central nervous system disorders) and adults with impairments such as stroke, who fall into the category of lacking capacity.

The topics we might focus on in interviews with surrogates/parents include:

- Any previous discussions with the disabled adult/young person that have informed their current choices.
- Their level of confidence about what the person would have wanted and how this affects decision-making.
- The role of the surrogate/parent's emotional state (both current and anticipated) in decision-making.
- How surrogates/parents balance the disabled child/adult's interests with their own interests and those of other family members.
- How they involve adults/young people who have limited capacity in the decisions.
- Other factors (for example, cultural, familial, level of understanding of information) that affect the surrogate's/parent's decisions.
- Influence of anticipated regret (see also Section 3 on emotion and decisionmaking).
- The role of information from and trust in professionals and others.
- Perception of pressure from others.
- Perception of time pressure and urgency of decisions.
- The way in which information is used.
- How the process of making the decision takes place, in particular which decisions are spontaneous without a process of deliberation, and which decisions are the outcome of a process of deliberation and why. What type of decision-making do they prefer?

## Shared decision-making

#### Shared decision-making: advice seeking

Shared decision-making (SDM) is the main term used to describe decision-making between a professional (typically a doctor) and a lay person (patient or other service user). There is an enormous literature on shared decision-making addressing questions such as: Why it is important? What is needed to achieve it? Does it really happen? What is it like to experience it? What are the outcomes of SDM?

Whilst shared decision-making is not the main focus of the panel study, the research will involve interviews with key individuals who have been involved in/supported decision-making. Jungerman and Fischer (2005) provide a useful model of understanding the dynamics of this particular joint decision-making situation, focusing particularly on whether or not expert advice is accepted or rejected. They suggest that 'informational asymmetry' characterises expert - non-expert decision-making situations (see Figure 4).

Advisor	Client
1. Generalized knowledge about	1. Individual knowledge about
client's problems.	personal problem.
<ol> <li>Extensive knowledge about relevant facts.</li> </ol>	<ol> <li>Little knowledge about relevant facts.</li> </ol>
<ol> <li>Statistical knowledge about client's goals and values.</li> </ol>	<ol> <li>Limited awareness about personal goals and values.</li> </ol>
<ol> <li>Professional experience with decision outcomes, coping behaviours, and client's biases.</li> </ol>	<ol> <li>Little, if any, experience with problem-related decision consequences, coping possibilities, and judgemental demands.</li> </ol>
<ol> <li>Explicit knowledge of decision strategies, implicit decision competence and routines.</li> </ol>	<ol> <li>No explicit procedural expertise, implicit (unrelated) competence.</li> </ol>
<ol> <li>Professional expertise with client's decision-making behaviour.</li> </ol>	<ol><li>Little, if any, experience with advisor's decision strategies</li></ol>

#### Figure 4: Differences in knowledge between advisor and client

(Jungerman and Fischer, 2005, p.159)

Jungerman and Fischer argue that this asymmetry prevents decision-making occurring according to traditional theories of decision-making and leads to different decision-making strategies being adopted. The 'uninformed client' does not have the access to information to weigh up options and, in a sense, is wanting to short cut that process by seeking expert advice. The expert, through their experience of being involved in numerous similar decisions, does not undertake an analytic examination of the options but instead the decision about which advice to give and which recommendations to make is rapid, using established heuristics. In essence, therefore, the two individuals involved in the decision-making process are using different strategies to achieve a decision. In addition, Jungerman and Fischer argue that the advisor (and not just the information they are imparting) plays a significant role in the decision taken, see Figure 5.

# Figure 5: Difference in decision-making strategies between advisor and client

Advisor	Client
<ol> <li>Is aware of client's         <ul> <li>(in)competence, relies on             experience and routines.</li> </ul> </li> </ol>	<ol> <li>Cannot and does not want to explore all the options, asks for advice.</li> </ol>
<ol> <li>Knows that a recommendation is expected, is prepared to explain and justify.</li> </ol>	<ol><li>Expects a recommendation (and is willing to pay for it).</li></ol>
3. Applies particular heuristics.	<ol> <li>Directs attention to recommended option, searches and stores information selectively.</li> </ol>
<ol> <li>Focuses on clients and their features, categorizes clients.</li> </ol>	<ol> <li>Focuses on advisors and their features, evaluate their credibility.</li> </ol>
<ol><li>Decision: recommendation of the matching option(s).</li></ol>	<ol><li>Decision: acceptance or rejection of the advice.</li></ol>

(Jungerman and Fischer, 2005, p.161)

Jungermann and Fischer (2005) proposed that four factors influence whether or not an individual accepts advice:

- The judgement of the advisor regarding the recommended option;
- The judgement of the client regarding the recommended option;
- The advisor's credibility and extent to which the client trusts the advisor;
- The client's confidence in his/her own judgement.

Research evidence produced by Jungermann and Fischer (2005) and others supports this model (for example, Sniezek and Buckley, 1995; Harvey *et al.*, 2000; Harvey and Fischer, 1997). For example, Oehler (1995) found that the quality of the advisors in a bank was rated as *more important* by customers than the bank's conditions and offers. Interestingly, perceived credibility of the institution in which the expert works can also affect whether or not advice is accepted (Sniezek and Buckley, 1995).

#### Implications for the Panel Study

Jungerman and Fischer's model provides a useful way of understanding how people involved in the panel study may use experts to assist with decision-making. It flags up the differences between this and other joint decision-making situations. In relation to the interviews with key individuals planned for the study, it would be interesting to explore with them their judgements and reasoning (specific to the person/family in question) in relation to the information and advice they provided and the strategies they used to support decision-making.

In relation to participants, issues of trust and credibility would be interesting to explore, especially where decisions were made against professional advice. Finally, this model assumes relative naivety. However, it could be argued that the people in the study are, or become during the course of the study, less naïve and more expert and perhaps more confident in their own judgements – it would be interesting to explore whether this happens over the duration of the project.

## **Decision-making within close relationships**

Theoretical models of decision-making do not yet properly explain or take account of decision-making in close relationships. In trying to understand this particular decision-making context we have therefore had to turn towards empirical research. The (potentially) relevant literature is a relatively diverse and difficult to identify. We summarise below some of the key approaches and areas of work which are likely to be of interest to the panel study.

#### The relevance of research on group decision-making

There is a large literature on group decision-making and this has been used to inform the development of theories of group decision-making and problem solving. However, most of this work is based on research which has used groups formed expressly for the purposes of a piece of research. In contrast, couples and families bring, amongst other things, pre-existing roles; a knowledge of each others' values, aspirations and expectations; and a history of joint decision-making to each decision-making situation. In addition, the relationship that exists between the two decision-makers will have a significant impact on the decision-making process. These key differences between 'experimental groups' and family units are clear obstacles to generalising from research on group decision-making to decision-making within families.

#### Dyadic decision-making: the relationship factor

Joint decision-making is a central feature of any close relationship. As Kirchler *et al.* (2001) note: 'decisions determine the quality of the relationship, and [that] conversely, the kind of decision-making process is determined by relationship quality' (p.227).

Dyadic decision-making is the term used to refer to decision-making within the context of a pre-existing, close relationship. Researchers argue that dyadic decision-

making is distinctly different to other 'configurations' of decision-making. The relationship between the two decision-makers is not only something that has to be taken account of within the decision making processes, but also impacts on the way decisions are achieved.

Summarising the findings of research (Kenny and Acitelli, 1989; Poole and Billingsley, 1989; Sillars and Kalhbesch, 1989), Cicirelli (2006) noted that the features of dyadic decision-making 'involved implicit understandings, limited discussion, abbreviated comments, mental shortcuts in thinking, and brief conversations to reach a quick decision rather than a long deliberation... [and that] decision-making was facilitated or hindered depending on the quality or closeness of the relationship between the two decision-makers' (p.209). Poole and Billingsley (1989) also found that maintaining the relationship could be as important (to one or both of the decision-makers) as making an effective decision (see also Kirchler *et al.*, 2001). Finally, findings from research suggest that the decision-making process is dominated by the dyad member with the greater power in the relationship, with that power arising from greater expertise, authority or interpersonal skills (March, 1994; Poole and Billingsley, 1989).

#### The relative importance of the relationship: an issue of power

It has been argued that within the parent-child relationship, the importance vested in the relationship by the two parties changes and develops over the life course: the socalled notion of 'developmental stake' (Bengston and Kuypers, 1971; Fingerman, 2001). Cicirelli (2006) suggests that among adult children and their elderly parents, adult children hold greater power because they have less vested in the relationship than the parent who may be dependent on them for care, social contact and so on. The impact of this power imbalance was observed by Cicirelli with respect to (hypothetical) dyadic care-giving decision situations. The adult child dominated the decision-making and, in situations of conflict, parents were significantly more likely to capitulate or compromise than the adult children (Cicirelli, 2006).

#### Decision-making between intimate couples

As well as more general research on dyadic decision-making, there are further bodies of research on decision-making between couples. This is neither cohesive nor consistently based on a set of theoretical frameworks. It tends to be located within specific topics and, with the exception of consumer behaviour research, is generally descriptive as opposed to theory-generating. It covers the following areas:

 Therapeutic research: typically focusing either on the way that inequities of power within the decision-making relationship can lead to relationship difficulties, or on interventions to improve negotiation and decision-making in relationships. This work is based on theoretical models of marital negotiation (for example, Godwin and Scanzoni, 1989).

- Sexual decision-making: there is a distinct body of work which examines contraceptive choice and other aspects of sexual decision-making (for example, Zak *et al.*, 1998; Miller and Pasta, 2001; Harvey *et al.*, 2003; Ko and Mueke, 2005). One of the key themes of this work has been to explore cultural differences in terms of perceived roles and issues of power and how that relates to joint or sole decision-making with respect to sexual behaviours.
- Prenatal genetic testing and fertility treatments: this is another significant body of research (for example, van Balen, 1997; Anderson, 1998; Sandelowski and Jones, 1996; Browner and Preloran, 1999; Kenen *et al.*, 2000). Almost all of it is descriptive, often retrospective, work and has typically been carried out with the purpose of informing good practice in counselling and information provision. In some cases, the male partner is cast in a supportive role as opposed to being seen as a joint player in the decision process. Interestingly (based on the outputs from the searches we conducted) there appears to be an absence of work on conflict reflecting, perhaps, that the research has captured the final decision and couples' feelings about and justifications for the decision, as opposed to exploring the decision process itself.
- Work/life balance and location: recent years has seen a growth of research in the way couples negotiate where they live and how they manage their work and family obligations. Within this body of work, decisions are sometimes 'rebranded' as compromises and research has tracked the way compromises are developed and achieved (for example, Challiol and Mignonac, 2005; Hardhill, 2002). Work in this area has also highlighted the emotional aspects of the decisions being made and the fact that, typically, other parties are involved in the decision-making process (for example, Adams, 2004).
- Consumer behaviour: over the years there has been quite a lot of research • looking at how couples go about making purchasing decisions. This has been explored both with respect to low cost (for example, restaurants/films) as well as higher cost (cars, houses) decisions. Some of the findings from this work would be appear to be relevant to our programme of work. Early work identified specialisation within couples with regard to purchasing decisions, depending on what was being purchased. Thus respective roles played in purchasing decisions were classified as husband dominant, wife dominant, syncratic (or shared), or autonomic. Davis and Rigaux (1974) refined this further by looking at marital roles at different phases of the decision-making process (that is, problem recognition, search for information, and final decision). They found that both men and women perceived their roles in the decision-making process to have been more specialised during the information-seeking stage, compared to the stages when a decision problem is first identified and when the final decision is taken. Thus, one partner might take the lead role (perhaps on the

basis of fore-knowledge, previous experience or availability of resources such as time) in refining the decision problem and collecting relevant information, but the actual decision is a shared one. More recent research has highlighted the cultural influences on decision-making roles. For example, husband dominance in decision-making prevails to a greater extent in less egalitarian societies (Green and Cunningham, 1980; Ford *et al.*, 1995).

Naturalistic research: Kirchler *et al.*, (2001) used the daily diary entries of 40 couples written over the course of a year and retrospective interviews to explore joint decision-making in everyday family life. They observed the process of decision-making by couples as being typically incremental: 'Partners move repeatedly from a desire, via discussions and evaluations, postponement and renewed discussion of a topic, to arrive at a decision. Sometimes, in the course of reaching a decision, one goal becomes lost in favour of another one' (p.235). What is interesting is that, when interviewed, the participants' descriptions of the decision process was much more simple and linear and they did not recount the deviations and circuitous routes by which the decision was achieved. In addition, they found differences between partners' accounts of a decision process.

Kirchler *et al.* (2001) also paint a vivid picture of decision-making in the context of everyday routines and activities. Couples reported that discussions (or arguments) about impending decisions typically took place in the course of carrying out everyday routines and activities (as opposed to discussions only taking place at a fixed or particular time/place and isolated from other aspects of family life). In addition a number of issues were typically being decided on during the same time period. They conclude: 'Decisions are not isolated events, but are bound up in the complexities of everyday life. Whilst a financial decision is being taken, various other differences of opinion are also being played out, and other everyday tasks repeatedly force their way to the forefront of discussions' (p.229). In addition, Kirchler *et al.* describe the concurrent (and sometimes conflicting) goals of wanting to achieve a decision that will preserve the relationship. Thus there are short and longer term goals of decision-making.

Kirchler *et al*'s. findings support the idea that specialist knowledge or a relative interest in a particular topic influences the level of influence each partner brings to a decision situation. However, Kirchler *et al.* also found that the views or desires of the less influential partner can prevail where the decision relates to something of special importance to them. In addition, Kirchler *et al.* also found that past decisions could, in situations of conflict or an incongruence of views, affect the decision taken. They found what could be described as 'turn-taking' in who had the final say over a decision. This was interpreted by Kirchler *et al.* as a means by which equality within the relationship was maintained over time.

#### Implications for the panel study

This is a fascinating area but, as yet, unlinked to theories of decision-making. However, there are clear links between the findings of the research reported above and the aspects of some of the decision theories we have described earlier (for example, the information processing approach and prospect theory).

The way the relationship itself becomes an important player (in a number of different ways) in the decision-making process is interesting and we need to make sure our topic guides and analysis allow for that to be properly explored. The research also flags up the fact that individuals' accounts of the same decision process may differ – perhaps a framing effect? We need to make sure our analytic approach can 'cope' with that.

The longitudinal nature of the project would allow us to explore the phenomenon of 'turn-taking' in decisions, changes and evolutions in what people have vested in their relationships, and how that affects decision-making.

The issue of dominance/specialisation in the information-seeking phase of decision making is interesting. The sorts of questions we might want to ask are: What happens when the person previously dominant in certain decision areas (for example, finances) is no longer able to/or is no longer around to lead on those decisions – what does the partner do, is the 'quality' of the decision-making jeopardised? Do other family members move in – perhaps those who specialise in that area within their own marriage/partnership (for example, the son, who leads in financial decision-making in his own marriage/partnership, taking over financial decision-making for parents after his father's severe stroke). A different set of questions would be: why, with respect to what sorts of decisions, and how, is dominance/specialism developed or assumed when a couple encounters an issue which is totally novel/new to their relationship (for example, medical treatment, entry to residential care)?

Finally, it is important to note Kirchler et al's. finding that recollections of a decisionprocess do not accurately reflect the actual process – we need to get behind the simplistic accounts and this requires finding ways of facilitating people to recall more accurately the decision process they went through.

## Appendix: Identifying the Literature

A search on the PsycInfo biographic database, using terms 'choice' and 'decision making', but restricted to humans and English language and publications from 1985 onwards, identified over 55,000 publications. An initial scan of these references showed that it would be difficult to realistically limit the search using conventional literature search and review strategies. We then met with Dr Dawn Dowding from the University of York's Department of Health Sciences whose field of expertise is theories of decision-making. She confirmed that this field is not one where a literature search of the conventional type is likely to be the best way to identify the key theories and the empirical literature supporting them. Much of the literature is in the form of books, as our initial search had shown (PsycInfo lists books and chapters as well as journal articles). Dr Dowding pointed us in the direction of the main theories and key texts and authors. In addition, we identified a scoping review of patient choice recently carried out for the NHS Service Development and Organisation (SDO) Research and Development programme (Fotacki et al., 2005). As part of this review, the authors also carried out a comprehensive search on theories of choice. Their results and the results of our reading of key texts concur in identifying the key theories relevant to decision-making and choice within the context of the Panel Study. We then read and summarised these and identified topics for further, more focused, searches. We also traced relevant empirical evidence related to these theories.

In addition, using PsycInfo, we carried out specific searches of the literature for research on the following topics which are pertinent to the Panel Study:

- the impact of emotion on choice/decision-making
- shared choice/decision-making
- cognitive capacity and choice/decision-making
- personality and choice/decision-making
- surrogate choice/decision-making
- parent choice/decision-making.

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