CENTRE FOR HEALTH PROGRAM EVALUATION

Determination of High Quality Long-Term Outcomes for people with Disabiling Conditions

Roy Batterham
Research Fellow, Program Evaluation Unit, CHPE

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The Co-ordinator
Centre for Health Program Evaluation
PO Box 477
West Heidelberg Vic 3081, Australia
Telephone + 61 3 9496 4433/4434   **Facsimile** + 61 3 9496 4424
E-mail CHPE@BusEco.monash.edu.au

ABSTRACT

This paper reports on the methodological development and preliminary results of a project which aims to define the desired long-term outcomes for people with disabilities in a form appropriate to be used for accountability purposes for rehabilitation and other services. Difficulties with current approaches to ensuring accountability are outlined. Particular emphasis is placed on difficulties that arise for disabled people when an inappropriately restricted range of goals are legitimated through the accountability system. Such a restriction is identified as a form of bias. The Concept Mapping System developed by Trochim (1987) is considered as a methodology for avoiding this bias whilst developing criteria for accountability. This method is discussed in terms of its basis in statistical, program evaluation and psychometric theory. Preliminary results of Concept Mapping groups with hospital-based rehabilitation staff are presented. While recognising that further research is necessary to establish how representative these findings are, it is noted that staff working with people with acquired brain injury (stroke and traumatic head injury) had a substantially greater focus on the 'meaning' aspects of their clients' lives than did staff working with people with back pain.

The proposed methodology for subsequent phases of the project is briefly outlined.

Determination of High Quality Long-term Outcomes for People with Disabling Conditions

Report on Rehabilitation, High Quality Outcomes Project

Introduction

Over the last twenty years there has been a continuing increase in awareness of the multiplicity of factors that impact upon an injured workers success in returning to work. Biological and psychological simplifications have been discredited (Vuiori and Rimpela, 1981). It is now recognised that a majority of people who fail to return to work do not have an unstable injury that would be exacerbated by activity (Rosomoff and Rosomoff, 1991). Similarly, while it is clear that people who receive compensation do, on average, less well than those who don't, it has become equally clear that the relationship between compensation and recovery is mediated by a whole range of social and structural factors—job satisfaction, job security, job threats, relationships with peers and supervisors, the type of industry and approaching retirement all effect return to work (Barnes et al, 1989; Greenough, 1993; Nykvist et al, 1991). Other important factors may include what workers are told by health professionals and an adversarial compensation system. From a systems perspective it is recognised that many of the factors that affect successful return to work are the same factors that influence injury prevention; the physical environment and worker morale are obvious examples(Rosomoff and Rosomoff, 1991).

Similar developments are true for people with more profound injuries. The attribution of behavioural and social problems of people with traumatic brain injury, solely to the acquired brain damage is now regarded as a gross oversimplification (Brown and Nell, 1992). The development of constructive or destructive patterns of behaviour is now most commonly attributed to the interaction between the physical and cognitive deficits of the individual and their experiences in dealing with health services and the wider community (Dikmen, Machamer and Temkin, 1993; Leftoff, 1983; Lewis, 1991). For severely injured individuals, success in developing a basis for their sense of identity that doesn't depend upon "physicality" and "performance" is essential (Keany and Glueckauf, 1993).

The complexity of factors which determine long-term outcomes has often forced service providers and funding agencies to depend upon very short-term measures of success for program management and accountability. This approach can be destructive in the long-term for three reasons:

1   the short-term measures chosen are often biased samples of the complex range of factors which determine long-term outcomes;

2   holding individual services accountable for a discrete set of short-term outcomes often leads to competition and poor collaboration between services;

3   the focus on short-term gains fails to consider the long-term aspirations of the client and can inhibit or misdirect motivation.

The remainder of this report refers to these three issues using the shorthand terms, bias or distortion, collaboration and motivation. It is necessary to define the sense in which these terms are used and briefly to summarise the key assumptions related to each.

Definitions and Assumptions

Bias, Distortion and Constriction

In this paper **bias** is taken to mean a failure to consider adequately all the issues that are important to a person's quality of life. In this sense the term can be applied to the opinions and approaches of individuals or groups of people, to measurement instruments, to programs or to accountability systems—anyone or anything that could be said to hold or to implicitly presume a certain view of quality of life. Often the term **distortion** will be used because it fits the spatial forms of analysis that are used. It should be treated as synonymous with the term bias. Sometimes the term **constriction** will be used to refer to an appropriate restriction of focus on certain quality of life domains for certain purposes. Bias and distortion refer to an inappropriate restriction where a global view is really required.

Collaboration

Collaboration refers to the ability of various parties to work together for the benefit of the injured individual and to achieve the desired long-term goals. **Intersectoral collaboration** indicates coordination of efforts between sectors, in particular between professionals in the health sector, employers and insurers. While this concept is vital for all rehabilitation, it is possibly the single most important issue affecting return-to-work outcomes for people with mild to moderate injuries. A key purpose of this research is to develop accountability systems that will facilitate rather than hinder this sort of collaboration.

Motivation, Morale, Utility Function

In this paper **motivation** is used to refer to a person's global judgement about what is in their best interests considering **all** aspects of their life. In this regard it is more like economists' concept of a **utility function** than it is like the common use of the term in phrases such as "motivated to work". Theories of motivation that are based on inappropriately restricted (ie **distorted**) conceptualisations of quality of life will frequently fail. Recent psychological theory highlights the fact that motivation is frequently determined by the individuals beliefs about the future and their own ability to achieve their aspirations (Bandura, 1977; Niven, 1994; Ajzen and Madden, 1986). This paper refers to the level of such belief as **morale**. Morale is considered to be a combination of beliefs that are often expressed in more technical terms such as self-efficacy, hopefulness and mastery and various mood factors.

The purpose of this project is to find ways to hold multiple services accountable for the long-term outcomes of their clients and thus to improve collaboration and results. For this discussion it is necessary to consider two more concepts.

Accountability Systems

It is well established that accountability systems end up defining and confining the goals of services (Campbell, 1979; Gabutcheon and Singh 1989, 1990). This has two implications. Firstly, it is essential to target the accountability system appropriately, (frequently this can be achieved by using consumers as arbiters in the system). Secondly, any accountability system requires ongoing servicing to make sure that the indicators and measures are continuing effectively to facilitate the ultimate goals of the services.

Indicators

Indicators are defined by their use. They are data elements which indicate or point to some more general aspect of a program, often for the purpose of monitoring effectiveness. Typically they are used to make comparisons between services or to monitor a service over time. Indicators can be objective, such as return to work rate, or subjective, such as job satisfaction. Self reported objective states are often mistaken for subjective indicators. In this report they are treated as objective indicators as are most psychometric tests. The term subjective indicator is used exclusively for someone's **judgements** about the quality or satisfactoriness of something, (often some aspect of their life).

This research is based upon five key assumptions. These are not discussed here but have wide support in the literature. These assumptions are:

1   Distortions in accountability systems are reproduced throughout the service system.

2   Distortions in the service system are reproduced in terms of dysfunctional effects on individual morale and motivation.

3   Accountability for short-term outcomes creates distortions and hinders intersectoral collaboration (Campbell, 1979).

4   The validity and adequacy of any indicator erodes as it is used within an accountability or funding system. On the one hand services begin to report information in a way that benefits them, on the other they find ways to play the system to their advantage (Ginsberg, 1984). This leads to the fifth assumption.

5   Accountability systems can not be maintained by technical means. Equitable political and social mechanisms for their control will always be necessary.

These five assumptions lead to one further assumption which provides the basis for this project.

> In order to establish a valid system of indicators it is necessary to identify a **comprehensive** set of desired outcomes which represent the concerns of all important stakeholder groups.

It is now possible to discuss the overall purpose of this project and the purpose of the various elements of the project.

Purpose

The purpose of this project is to develop and validate a framework for the assessment of high quality outcomes after rehabilitation and to identify a valid, parsimonious and serviceable set of indicators and measures of high quality, long-term outcomes. The purpose of both the framework and the indicators will be to facilitate the coordination of the efforts of multiple services to meet the client's long-term needs. The system will use a combination of objective and subjective indicators and should allow valid comparisons to be made between industry sectors and companies on important indicators such as long-term return to work and job satisfaction. This would facilitate the development of innovative approaches and the identification of models of best practice which warrant development and dissemination.

Overall Structure of the Project

The requirements of such a project are complex. Development needs to occur within four areas. Firstly there needs to be local work at one or two sites to develop ideas and methodologies. Secondly there needs to be work to establish how representative the ideas identified at these sites are of ideas held in the wider community. Third there is a need for theoretical development in certain key areas. Finally the framework that is developed needs to be tested locally and with individuals to ensure that it is not just a statistical abstraction but that it has meaning in the lives of individuals. The elements of this process are listed in Table 5 in the final section. Methodological detail remains to be worked out for some sections.

Stage 1 - Concept Mapping on the Perceptions of High Quality Outcomes of Stakeholder Groups

Purpose

The first stage of this project has two main purposes:

- to develop a comprehensive pool of items which are considered to constitute a high quality outcome for three conditions; chronic back pain, head injury and stroke;

- to get a preliminary idea of how different stakeholder groups, (patients, families, hospital and community based service providers, funders), conceptualise a high quality outcome for these conditions.

The three conditions were selected because they were thought to be as different as possible which should enhance our ability to identify an overall 'structure' for quality of life. (See discussion on divergences below.) The contrasting conditions should also make it easier to characterise the way different groups conceptualise high quality outcomes, through comparative methods. An extensive review of the literature on long-term outcomes and other methodological and theoretical developments is being pursued concurrently with this process.

Methods

The primary method is based upon "The Concept Mapping System" (CMS) developed by Trochim (1987). This is a comprehensive method which includes instructions and software for data collection, entry, analysis and interpretation. It is a process in which the group of interest brainstorms statements relevant to the question at hand and are then intimately involved in constructing an interpretation of the results.

The product of the process is a two dimensional map in which conceptually related items sit close to each other whereas conceptually distinct items sit far apart. The maps show groups of related outcomes and something about the relationships between these outcome domains. It is possible to look at the maps at a variety of "resolutions". Large, abstract categories can be identified, similar to the quality of life domains seen in many instruments,

FIGURE 1

The Concept Mapping Process (Source: Trochim 1989)

Step 1

Preparation
Selecting the participants
Developing the focus
- Focus for brainstorming
- Focus for rating

Step 2

Generation of Statements

- Brainstorming

Step 3

Structuring of Statements

- Sorting statements
- Rating statements

Step 4

Representation of Statements

- Computation of Maps

Step 5

Interpretation of Maps
- The statement list
- The cluster list
- Naming the clusters
- The point map
- The cluster map
- The point rating map
- The cluster rating map

Step 6

Utilization of Maps
For Planning
- Action plans
- Planning group structure
- Needs assessment
- Program development
For Evaluation
- Program development
- Measurement
- Sampling
- Outcome assessment

or more precise outcomes can be identified right down to the level of the individual brainstormed statements. The two dimensional maps developed so far in this project can be seen on pages 15, 19 and 23.

Rationale

The Statistical Basis

The statistical processes used to develop the maps are non-metric multi-dimensional scaling (MDS) and cluster analysis. Multi-dimensional scaling and scaling and cluster analysis are members of a family of statistical techniques designed to display, in visual form, the relationships between a large number of variables and to detect patterns which underlie their arrangement (Kruskal and Wish, 1978). Even sophisticated modelling procedures such as structural equation modelling (SEM) are unable to handle large numbers of mutually interacting variables (Tetrick, 1992). Similarly the human mind cannot comprehend these relationships when expressed in narrative or numeric form. Spatial displays can make these arrangements accessible to interpretation. It must be noted that these techniques **display** information; they can suggest theories and can suggest patterns against which theories can be tested, but they cannot be used alone for theory testing and validation.

Formal theory testing would require reduction of the number of variables. Statisticians and systems theorists would handle this in two different ways. Statisticians would generally use the items in particular outcome domains to construct scales to measure those domains. The development of measuring instruments in this way is a common and legitimate use of MDS. Systems theorists would develop dynamic models based on a review of the best available theory and using the largest domains that enabled the model to work. They would then repeat the process, modelling within each domain and so on (Levine, VanSell and Rubin, 1992). A third method of reduction is to use cluster analysis based on empirically observed outcomes. The later stages of this project will use all three approaches.

The Evaluation Theory Basis

The Concept Mapping System was developed in the context of a nearly universal movement within the evaluation community to base evaluation firmly on theories of how programs are supposed to achieve their effects. Two aspects of theory are typically discussed, normative theory, which is related to notions of best practise and describes how the program should be run and what it should achieve, and causative theory which describes the mechanisms which **could plausibly be activated** to produce an effect. One important aspect of normative theory has been called normative outcome theory.

At first glance the term 'normative outcome theory' (Chen, 1990; Chen & Rossi, 1987) seems like a grandiose neologism for 'goals'. On closer acquaintance however the term covers a substantial area of inquiry. Its foci include:
- the relationship between the rhetorical, real and operative goals of the program;

- valuing:

    - a non-prescriptive approach, examining the differing goals of various stakeholders and the processes by which certain goals come to be emphasised;

-      a prescriptive approach, examining the relationship between goals and need;

- elements of causal theory which relate to the validity of intermediate goals as steps towards the ultimate goals;

- negative outcomes.

Concept mapping, as a tool for developing normative outcome theories, is considered a valuable means to avoid the effects of distortion discussed above. It has also been used to identify outcome patterns for the purpose of strengthening causal inferences in both quantitative and qualitative studies (Cracelli, 1986; Trochim, 1985,1989a, 1989b). It has been used widely for curriculum development for professional training and for the development of professional competency standards. Its use in defining outcome standards for rehabilitation is conceptually very similar.

Psychometric Issues

Analysis of MDS plots proceeds in a fashion and using criteria analogous to standard psychometric approaches. Instrument development typically has two concerns, What items should be grouped together and on what basis? (ie do the items measure some common underlying entity?); and, What items should be kept apart and on what basis? (ie Does the instrument distinguish between different underlying entities?) The questions for MDS are the same, What causes items to be grouped together? and, What causes them to be located far apart? Groups of items that are conceptually similar and sit close together are called clusters or domains. The axes of the map—eg the thing that distinguishes the items at the top from items at the bottom, or diagonally opposite corners, or left from right—are called dimensions. In short, domains group, dimensions distinguish. The combination of domains and dimensions is called the 'structure' of the concept. Domains can help us to develop appropriate measuring instruments. Dimensions can help identify and protect against distortions in instruments, program assumptions or program design.

Quality of life research has largely been driven by what has been called the function feeling model (Culyer, 1990). This model suggests that the main dimension distinguishing different outcome domains is the distinction between functional outcomes and the individuals subjective states, particularly pain and positive and negative affect. There are however other dimensions which may be important in distinguishing outcomes; individual vs social, physical vs psychological, internal rewards vs external rewards and so on. Identifying which domains are important empirically can help to ensure the identification of a comprehensive set of outcomes, and to identify and characterise distortions. An example will make this clearer. If we found that function vs feeling and individual vs social were two key outcome dimensions we could map this as in figure 2. Important outcomes could be identified in all quadrants. If an instrument or a group of people or a program were to focus only on the items in the shaded area that would be a distortion. (This is not to say that this is not appropriate for some circumstances; it is only problematic where it causes other aspects to be neglected.)

FIGURE 2
Example Map Showing Two Dimensions and a Possible Distortion
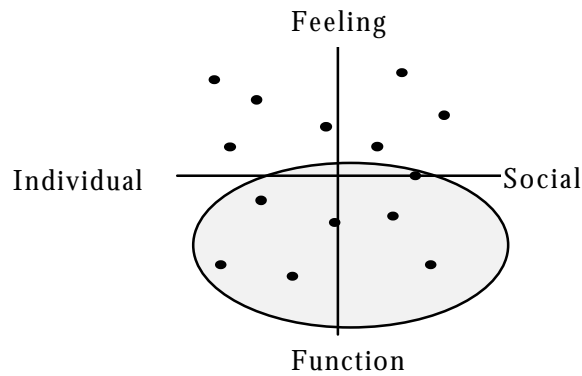
Modifications to the Standard Method

Identifying the important dimensions of high quality outcomes is an important element of this study for this reason three and four dimensional solutions of the results of each group were examined. The results of the three dimensional solutions will be presented in a future paper. The researcher was unable to identify any conceptually meaningful distinctions in solutions of four or more dimensions.

Minor modifications to the CMS procedures described by Trochim were adopted in order to minimise the burden on participants. Maps were constructed in two two, hour sessions and participants completed the sorting and rating tasks in their own time between these sessions. It is anticipated that some further modifications will be necessary with the patient groups.

Report on Concept Mapping of High Quality Outcomes With Hospital Based Service Providers

Introduction

To date concept maps have been developed and analysed with groups of rehabilitation professionals from Royal Melbourne Hospital, Essendon Campus for each of the three focus conditions.

Method

After an initial information and planning session staff were recruited by volunteers from the hospital to participate in the concept mapping groups. There was an attempt to get representatives from each main treating discipline from within the hospital who had significant expertise and experience working with people with back pain. Participants in the initial brain storming sessions for each condition are listed in table 2.

The initial session with each group was two hours. After a brief introduction participants were asked to individually brainstorm statements in response to the following seeding statement[1].

> **Thinking as broadly as possible generate statements which describe aspects of desirable long-term outcomes for people after a back pain.**
>
> **Long-term - more than two years after discharge from inpatient care.**

After a short period of time another overhead was put up with the following prompts added to the seeding statement.

> **Consider:**
>
> **Things they can and can't do.**
> **Experiences they have had or have avoided.**
> **Feelings they have had or not had.**
> **Effects on their immediate or broader social environment.**

Participants were asked to avoid statements that contained many ideas, rather to separate them into a number of statements. After a period of individual brainstorming participants were asked to share their ideas with the group. Between fifty nine and sixty five statements were generated in each group (see results). These were then printed onto cards and rating sheets.

TABLE 1
Participants in Concept Mapping Groups

	Back pain	TBI	Stroke
Social Work	1	1	1
Rehabilitation Nursing	1	1	1
Rehabilitation Medicine	1	1	1
Speech pathology		1	1
Physiotherapy	1	1	1
Occupational Therapy	2	1	1
Vocational Counselling	1		
Psychology	1	1	
Recreation		1	

Between sessions participants were asked to complete a sorting task and a rating task. Firstly they were asked to sort the pile of cards into piles according to any system that made sense to them. The only constraints were that there had to be more than one pile and less than sixty two piles. Although there could be piles of one card no miscellaneous pile was permitted.

Participants were also asked to rate each item according to two sets of criteria. The rating guidelines are shown in figure 3.

The results of the sorting and rating tasks were forwarded to the primary investigator for preparatory analysis. With the stroke group two extra people completed the sorting and rating tasks in order to give more satisfactory numbers.

How important is this outcome?

(5)   Extremely important
(4)   Very important
(3)   Quite important
(2)   Desirable
(1)   Not important at all

How important is the contribution of hospital-based rehabilitation services to achieving this outcome? ('Hospital-based' includes both inpatient and outpatient services.)

(5)   Rehabilitation services are vital
(4)   Rehabilitation services are very important
(3)   Rehabilitation services have a role to play
(2)   Other factors are much more important than rehabilitation services
(1)   Rehabilitation services do not really affect this

Data Analysis

The first analysis was carried out using the Concept Mapping System software. This software handles data entry and arrangement and performs a multi-dimensional scaling analysis and cluster analysis. This program produces a two dimensional map. Groups of items which sit closest together are identified by the cluster analysis procedure. A three dimensional scaling solution and dimensional data were obtained using SAS. The stress value for a MDS solution is a measure of how far the distances between points in two or three dimensional space are from the true distances (ie how much adjustment of distances was required). Stress values for the three analyses for the three groups are shown in table 1.

TABLE 2
Stress Values for Multidimensional Scaling Solutions

Analysis	Stress		
	Back pain	TBI	Stroke
Concept Mapping System (2 dimensional)	.25	.28	.27
SAS 2 dimensional	.25	.23	.27
SAS 3 dimensional	.14	.16	.18

For all groups there is a substantial improvement in fit between the 2 dimensional solutions and the 3 dimensional solution. The three dimensional solution also seemed to have greater explanatory power on visual examination so it was decided to use this analysis as an extension of the normal Concept Mapping analysis. Stress values for the two 2 dimensional solutions were very similar.

The primary investigator prepared interpretations of both the 2 dimensional and three dimensional solutions. Materials were prepared for presentation to each group which represented a solution that made sense to the investigator. For the back pain group this was a seventeen cluster solution, for the head injury group it was a thirteen cluster solution and for the stroke group, a fourteen cluster solution. No clusters were amalgamated or artificially split by the investigator.

Interpretation Session

A second workshop was held with each group to develop an interpretation of the clusters and maps (Figure 1). The tasks in these sessions were as follows:

1   To modify clusters which seem not to make sense or to relocate items in more suitable clusters.

2   To name the remaining clusters.

3   To identify major regions on the map that indicate broader outcome domains.

4   To identify axes on the maps (dimensions that distinguish opposite areas on the map).

5   To develop an interpretation of the map (this included suggesting possible causal connections using the bridging values of items and clusters as a starting point. Items with high bridging scores are items that are placed in different clusters by different people completing the sorting task. Often they involve concepts which link or depend upon two or more other concepts).

The discussion in these workshops was tape recorded.

Results

This section presents the cluster solutions, maps and ratings for each condition. It is divided into three sections:

Pages 15-26 contain the cluster lists and two dimensional maps. For each condition a basic map showing just the named clusters is included followed by a map which includes the regions and dimensions that were identified. A list of clusters and the items included in each cluster is on the facing page. For each item the number of the original cluster and the cluster to which the item was assigned in the modified solution developed by the group, is listed.

On the maps large numbers label the clusters, small numbers relate to items and circled numbers indicate the clusters to which an item was moved by the group.
Pages 27-29 show the importance and importance of rehab ratings for each condition. On the ratings maps more layers in a cluster indicates greater importance. In the tables clusters with an average importance rating of more than 3.9 are shaded.

Two Dimensional Solution for Back Pain Group

Finances
-7

Employment 6

Legal
·2

Mobility 9 10 ADL
11
Fitness and Health

Medication (Education) 3

Medical-Self Management 1

Psych. Adjustment - SM 5

4 Personal Responsibility

Coping Skills

Sexual Relationships
·14

Family Relationships
Family Education 12

13 Social Supports

10 15
17
5
15 58

50 22
16 13
12 8

Leisure

Back Pain
Rehab. Hospital Staff
17 Cluster Solution

ADL

MEDICO-LEGAL

Finances
-7 Employment 6

OCCUPATIONAL

Legal ·2

Mobility 9 10 ADL
11
Fitness and Health

ADL

Medication (Education) 3

MEDICAL

Medical-Self Management 1

Psych. Adjustment - SM 5

4

Coping Skills

Sexual Relationships
·14

SOCIAL

Family Relationships
Family Education 12

13 Social Supports

10 15
17
5
15 58

50 22
16 13
12 8

Leisure

SOCIAL

PERSONAL & PSYCHOLOGICAL ADJUSTMENT

Personal Responsibility

Back Pain
Rehab. Hospital Staff
17 Cluster Solution

Final Cluster Solution for Back Pain Group

Var	Outcome	Orig	Mod
ν	**Medical - Self management**		
V1	Maintain relationship with same GP, specialist, rehab provider (as opposed to shopping around)	1	1
V35	Encourage independence in self management and decreased dependence on system	1	1
V40	Decrease dependence on medical and like facilities	1	1
V48	Decrease frustration with "the system"	1	1
V50	Be able to leave support network and go on holiday	16	1
ν	**Legal**		
V49	Completion of legal involvement	2	2
ν	**Medication (Education)**		
V9	Avoid addictive analgesia including alcohol	3	3
V27	To ensure adequate understanding or back care principles and manual handling as relates to home, work and function	3	3
V31	Decrease dependence on medication	3	3
V57	to have a good understanding of current medication program	3	3
ν	**Personal responsibility**		
V17	Ability to request assistance appropriately when period of recurrence or aggravation	4	4
V52	To be able to request assistance if required	4	4
V54	To maintain sufficiently elevated mood, to be able to record enjoyment and activities	4	4
V60	For anxiety levels to be under sufficient control - to be able to engage in activity without the need for medications	4	4
V67	For anger management to be sufficient to maintain appropriate social interactions	4	4
ν	**Psychological adjustment**		
V19	To change negative thought processes and behaviours that interfere with rehab	5	5
V23	Decrease frequency of pain behaviours	5	5
V24	Ability to make choices of lifestyle options	5	5
V32	Improvement in self esteem	5	5
V42	Maintain a non pain focused lifestyle (as per conversational topic)	5	5
V43	Have an improved feeling of self worth	5	5
V44	Improve confidence to try new things and break out of pain cycle	5	5
V59	continue psychological acceptance and adjustment to pain	5	5
V62	to identify stresses and relaxes	5	5
V64	To increase level of inner control and decreased pain control of their life	5	5
V65	To maintain a personally satisfying control over decision making	5	5
ν	**Employment**		
V3	To return to previous work capacity	6	6
V5	To consider re-training schemes	6	6
V12	To maintain roles in workplace	6	6
V20	To maintain support workplace relationships	6	6
V21	Unemployed - consider voluntary work	6	6
V25	Maintain or initiate satisfactory relationship with employer leading to income production and job	6	6

Var	Outcome	Orig	Mod
	satisfaction if possible		
V30	To engage in meaningful work related tasks	6	6
V39	To return to work without extra sick leave requirements	6	6
V41	Return to suitable occupation - paid or unpaid	6	6
V66	To be able to achieve career goals	6	6
ν	**Finances**		
V16	Control and/or independence finances	7	7
V47	Be economically independent	7	7
ν	**Undecided between clusters 6 and 10**		
V46	To develop a daily routine especially for those who are not in a RTW	8	8
ν	**Mobility**		
V2	Continue mobility ie. ambulation	9	9
V10	Able to drive a car or access public transport	9	9
V11	To improve basic level of function ie. sitting, standing walking tolerance	9	9
ν	**ADL**		
V15	Increase daily relaxation and quality of sleep	17	10
V26	To achieve or maintained independence of personal ADL OR domestic ADL	10	10
V28	To remain independent in personal care	10	10
V36	to be independent in domestic and community ADL	10	10
V45	to be successful in self monitoring physical condition	10	10
ν	**Fitness and health**		
V13	Maintain exercise programs as required	11	11
V33	Maintain correct weight	11	11
V51	To increase general fitness and thus beneficial exercise	11	11
V55	Maintain regular exercise and health diet	11	11
ν	**Family (2 poles, family relationships and family education)**		
V4	To maintain relationships pre-existing both family and social	12	12
V8	Understanding of chronic pain by family or significant others	16	12
V14	To join in family activities	12	12
V37	Involve family members in back care education	12	12
V38	Involve family in pain management techniques	12	12
V63	Maintain the role in the family	12	12
ν	**Social supports**		
V7	More leisure time with families	13	13
V22	Avoidance of social isolation	16	13
V29	To gain knowledge of community resources	13	13
V34	To have a social support network, maintained established and evolving	13	13
ν	**Sexual relationships**		
V61	To maintain a healthy sex life	14	14
ν	**Leisure**		
V6	To engage in previously enjoyed recreational activities	15	15
V18	To be involved in recreation as frequently as liked, and when and where	15	15
V53	Join a library	15	15
V56	Participation non library community based programs	15	15

Var	Outcome	Orig	Mod
ν	**Remnant of clusters 16 and17 - undecided between clusters 5 and 15**		
V58	Maintain interests outside their own condition and pain	17	17

Two Dimensional Solution for Head Injury Group

IDEATIONAL - PERSON

Health Knowledge

Future Goals

AWARENESS & ADJUSTMENT

Insight and Self Monitoring

Self Sufficiency

Personal Motivation

RELATIONSHIPS

HARD

Independant Living

SOFT

Social Skills

Self Expression

Choice

Communication

Recreation and Leisure

Family Issues

ADL

Supports

Childcare

Vocational

Previous residence

PRACTICE

13 Cluster Solution
Head Injury
Rehabilitation Hospital Staff

Health Knowledge

Future Goals

AWARENESS & ADJUSTMENT

Insight and Self Monitoring

Self Sufficiency

Personal Motivation

RELATIONSHIPS

HARD

Independant Living

SOFT

Social Skills

Self Expression

Choice

Communication

Recreation and Leisure

Family Issues

ADL

Supports

Childcare

Vocational

Previous residence

PRACTICE

13 Cluster Solution
Head Injury
Rehabilitation Hospital Staff

Final Cluster Solution for Head Injury Group

Var	Statement	Orig	Mod
ν	**Social skills**		
V1	maintenance of pre-accident social contacts	1	1
V8	Have established meaningful relationships in a variety of communities eg. home, club	1	1
V14	Return to previous social life	1	1
V28	An ability to make new friends and social contacts	1	1
ν	**Self expression**		
V17	The person will able to pursue any chosen areas or activities of interest independently	2	2
V41	Communication skills sufficiently functional to meet social needs	2	2
V52	The maintenance and development of personally acceptable sexual opportunities	2	2
ν	**Health knowledge**		
V9	Understanding of the nature of their injury and the recovery process	3	3
V47	Absence of medical sequelae such as headache, epilepsy and visual disturbances	3	3
V50	Regain physical and mental endurance that is absence of fatigue	3	3
ν	**Personal motivation**		
V27	The HI person assumes an active role within the rehab team	4	4
V33	Able to access social resources at a level acceptable for the person	4	4
ν	**Family issues**		
V2	Return to family life	5	5
V19	Balance between the family accommodating for the HI person and the HI person accommodating for the family	5	5
V23	For their carer to be able to maintain a life of their own	5	5
V32	Maintenance of family structure	5	5
V35	Tolerance of family members reactions to the accident or injury	5	5
V57	Carer to have sufficient knowledge and support / information support services and respite care	5	5
V58	Independence or participation in the care of the person's children	13	5
ν	**Insight and self monitoring**		
V11	Awareness of limitations of a behavioural and cognitive nature and how to deal with these issues	6	6
V15	The individual has an interest whether it be return to work or social interest	6	6
V29	Acceptance of changes and an ability to adjust expectations	6	6
V40	Confident in their ability to tackle new tasks	6	6
V42	Regained previous ability to cope with stress	6	6
V51	To be self motivated and to be able to self monitor	6	6
V59	To have accepted changes in lifestyle or ability	6	6
V62	Absence of slowness in thinking or reacting	6	6
ν	**Future goals**		
V34	Have established long-term direction or goals	7	7
V36	Ability to be socially appropriate behaviourally and emotionally	7	7
V53	To have the ability to engage in new pursuits ie. new learning activities	7	7
V56	Regain ability to cope with change in routine	7	7
ν	**Self sufficiency**		

Var	Statement	Orig	Mod
V18	The person will not reliant on professional health services for emotional and social needs	8	8
V21	To have sufficient self confidence and self esteem to be able to be involved in meaningful interpersonal, sexual relationships and social activities	8	8
V25	To feel able to exercise what that person would consider an acceptable degree of control over personal administrative affairs and major life decisions	8	8
V45	Development of personally acceptable sleep patterns	8	8

ν   Independent living

Var	Statement	Orig	Mod
V3	As independent in living as possible	9	9
V4	Optimal physical independence	9	9
V16	Return to previous residence	12	9
V24	To return to driving if applicable	9	9
V38	The use of equipment or aides to gain maximal independence if appropriate	9	9
V46	Return, whenever possible to independent living or supportive contexts	9	9
V54	To be safe in any environment	9	9
V61	Independent use of public transport	9	9

ν   ADL

Var	Statement	Orig	Mod
V5	The individual can function safely in the home environment	10	10
V6	Independence in personal care eg. showering and dressing	10	10
V7	Can perform activities of daily living eg. dressing, eating, bathing at a level acceptable to that person	10	10
V22	To be as independent as possible in daily living	10	10
V39	Participation / independence in domestic ADL tasks	10	10
V49	An ability to manage own money handling, budgeting	10	10
V55	An ability to participate in community ADL activities such as shopping	10	10

ν   Recreation and leisure

Var	Statement	Orig	Mod
V10	Return to previous or alternative recreational pursuits	11	11
V13	Return to previous leisure activities	11	11
V26	Able to self initiate or have opportunities for positive leisure experiences	11	11
V44	Return to activities that the person enjoys	11	11

ν   Vocational

Var	Statement	Orig	Mod
V12	Return to previous work activities	12	12
V20	Return to previous or alternative paid employment	12	12
V37	An ability to return to paid employment or alternatively have creative recreational outlets	12	12
V60	Return to study if applicable	12	12

ν   Supports

Var	Statement	Orig	Mod
V30	The carer is well informed and trained to provide optimal care	13	13
V31	Necessary support services are maintained over a long period of time	13	13
V43	Have available sufficient support from community based organisations or to have access to such groups	13	13
V48	To be knowledgable about disability services, access, advocacy and counselling services	3	13

Two Dimensional Solution for Stroke Group

Basic Function
AOL
7
Physical
Communication
48
54
10
Outdoor/General Mobility
9
17
1
12
8
32
6
Meaningful Activity
34
13
5
11
*14
Confidence
4
Vocational Avocational
Psycho-Social
Medical
1
2
3
Family

Adjustment/Acceptance

14 Cluster Solution
Stroke
Rehabilitation Hospital Staff

PHYSICAL
Basic Function
AOL
7
Physical
Physical Function
Communication
48
54
Outdoor/General Mobility
10
9
17
8
32
MEDICAL
C1
12
6
Meaningful Activity
34
Access
8
COMMUNITY
13
5
11
*14
Confidence
4
Vocational Avocational
Psycho-Social
Medical
1
2
3
Family
Adjustment/Acceptance
PSYCHO-SOCIAL

14 Cluster Solution
Stroke
Rehabilitation Hospital Staff

Final Cluster Solution for Stroke Group

| Var	Statement	Orig	Mod
ν	**Adjustment acceptance (1,2,3 merged) - Family items**		
V1	adjustment back into role of family	1	1
V13	have a defined and comfortable role within the family and social group	2	2
V18	still see family as family, not just carers - maintain normal family roles	2	2
V22	feel that family members still value what they have to offer even if its not the same as it was before the disability	1	1
ν	**Adjustment acceptance (1,2,3 merged) - Psychosocial adjustment items**		
V12	have control over life, good self esteem	1	1
V17	able to communicate difficulties and frustrations and be aware that these cant be affected or changed and that they will continue to exist	10	1
V24	have an acceptance of themselves and their lifestyle	1	1
V31	have dealt with the loss and grief of the stroke	1	1
V21	to achieve psycho-social adjustment (albeit with assistance)	2	2
V27	means of keeping themselves stimulated	2	2
V38	to be able to progressively decide upon new goals regarding lifestyle changes and be able to utilise resources to act upon them	2	2
V14	acceptance within a social group	3	3
V15	involved in pre-morbid relationships to a level that is significantly meaningful	3	3
V30	financial stability	3	3
ν	**Vocational/avocational**		
V3	return to work	4	4
V7	return to hobbies or recreational activities	4	4
V8	participate in leisure activities	5	4
V16	to be confident to operate within the community (outside home)	4	4
V29	involved in avocational interests (pre-morbid or post-stroke interest)	4	4
V51	being integrated back into usual pre-morbid community activities	4	4
V53	reintegrated into work, school or social life	4	4
ν	**Access (5 and 6 merged)**		
V19	access to community- physical, psychological, social communication	5	5
V26	to be able to make choices about preferences as a consumer	5	5
V33	return to driving or be independent in the use of alternative transport	5	5
V40	to be able to access appropriate supports	5	5
V32	have access to assistance as required - know where to go for help	8	6
V39	to be able to access adequate supports	6	6
V44	to have access to adequate vocational supports	6	6
V52	to have access to public transport and community facilities	6	6
ν	**Basic function (note physical and ADL poles)**		
V2	manage activities of daily living you want control of	7	7
V4	independent in personal care tasks showering, dressing, grooming and feeding	7	7
V9	independent of mobility about the home	7	7
V20	able to manage dysfunction upper limb as regards tone and shoulder care during daily routine	7	7
V28	to be able to move without excess effort	7	7

Var	Statement	Orig	Mod
V41	transfer independently	7	7
V47	able to prepare a simple meal (own cup of tea)	7	7
V50	to be able to move around without the anxiety or fear of falling	7	7
V54	to achieve domestic independence	8	7

ν Advocacy (single item from dismantled cluster 8)

Var	Statement	Orig	Mod
V48	to have adequate advocacy	8	8

ν Outdoor/general mobility

Var	Statement	Orig	Mod
V42	not limited by lack of physical endurance	9	9
V46	independently mobile in the community	9	9
V49	to get out of the house	9	9

ν Communication

Var	Statement	Orig	Mod
V5	to be able to communicate with family and friends	10	10
V10	to be able to communicate with others in the community	10	10
V45	can communicate in a functional way	10	10

ν Confidence

Var	Statement	Orig	Mod
V6	feel confident about spending time with other people in a social situation without the supervision or presence of a carer	11	11
V34	the confidence to seek advice and information	8	11
V37	not scared to try new experiences	11	11
V43	to have an understanding of underlying deficits and be able to maximise potential to attempt and complete tasks	11	11

ν Meaningful activity

Var	Statement	Orig	Mod
V11	able to initiate a task irrespective of its perceived value and complete it with a sense of contribution and accomplishment eg peeling carrots	12	12
V25	have established a daily routine of meaningful activity	12	12
V55	to have access to emotional supports	12	12

ν Medical (13 and 14 merged)

| Var	Statement	Orig	Mod
V23	have a good understanding of the medical issues and medications	13	13
V36	remove fear of recurrence	13	13
V56	feel confident to seek medical advice as required	13	13
V58	family members/friends understanding the persons deficits and how to handle them	13	13
V59	family and carers have access to adequate supports	13	13
V35	have medical problems stabilised	14	14
V57	medically stable	14	14

Ratings for All Groups
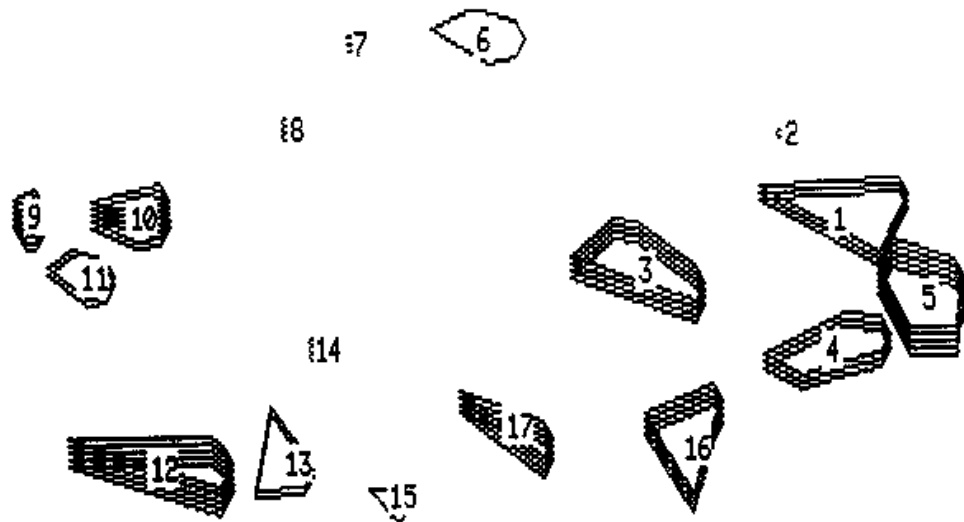
Ratings for 17 Cluster Solution
Back Pain
Rehabilitation Hospital Staff

	Import. Outcome	Range for items	Import. Rehab.	Range for items
BACK PAIN				
Medical-Self Management (1+ it 50)	3.70	3.00-4.13	3.32	2.63-3.75
Legal (2)	3.25	3.25	2	2
Medication (Education) (3)	4.13	3.88-4.38	4.00	3.63-4.63
Personal Responsibility (4)	3.83	3.13-4.25	3.60	3.25-4.25
Psych. adjustment-Self Management (5)	4.4		3.88	
(5 + it 58)	4.38	3.88-4.88	3.86	3.25-4.25
Employment (6)	3.33	2.75-4.13	3.45	2.88-4.50
Finances (7)	3.94	3.75-4.13	2.31	2.25-2.38
Daily Routine (8)	3.75	3.75	3.13	3.13
Mobility (9)	4.48	4.25-4.75	3.96	3.63-4.25
Activities of Daily Living (10+it 15)	4.18	3.88-4.63	4.0	3.5-4.5
Fitness and Health (11)	3.56	3.0-3.88	3.66	3.13-4.0
Family Relationships (12 + it 8) and Education	4.28	4.13-4.38	3.6	2.63-4.38
Social Supports (13 + it 22)	3.8	3.25-4.63	3.11	2.43-3.88
Sexual Relationships (14)	3.88	3.88	3.25	3.25
Leisure..(15)	3.16	1.63-4.0	2.97	2.0-3.63
(15 + it 58)	3.35	1.63-4.13	3.1	
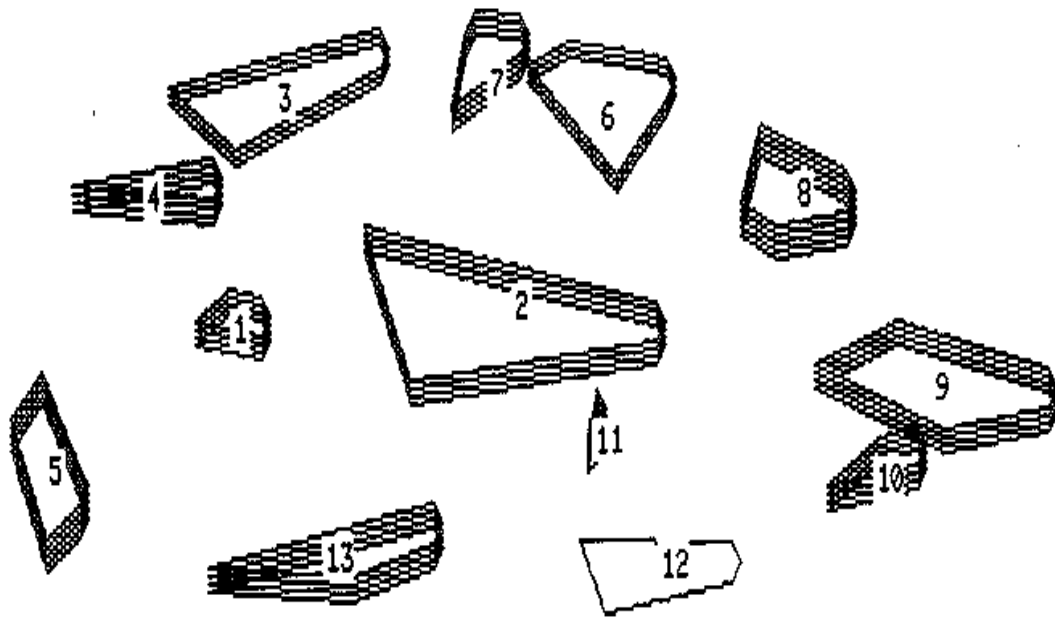
Ratings for 13 Cluster Solution
Head Injury
Rehabilitation Hospital Staff

	Import. Outcome	Range for items	Import. Rehab.	Range for items
HEAD INJURY				
Social Skills (1)	4.00	3.88-4.13	3.19	2.88-3.50
Self Expression (2)	3.96	3.63-4.25	3.46	2.75-4.25
Health and Knowledge (3 -item 48+ item 45)	3.82	3.75-4.00		
Personal Motivation (4)	3.94	3.75-4.13	3.63	3.38-3.88
Family Issues (5)	4.08	3.5-4.75	3.38	3.00-3.63
Insight and Self Monitoring (6)	3.86	3.13-4.38	3.45	2.88-4.50
Future Goals (7)	4.00	3.88-4.38	3.47	3.25-3.75
Self Sufficiency (8 -item 16)	4.38	3.88-4.88	3.54	3.38-3.75
Independent Living (9 +item 16)	3.78	2.63-4.75	3.97	2.88-4.63
Transport items	3.13	3.00-3.25	3.94	3.63-4.25
Non-transport (-item 16)	4.33	4.00-4.75	4.20	3.63-4.63
Activities of Daily Living (10)	3.89	3.38-4.38	4.21	3.88-4.50
Recreation and Leisure (11)	4.16	4.00-4.25	3.56	3.38-3.75
Vocational (12 -item 16)	3.38	3.00-4.38	3.53	3.25-3.75
Supports..(13 + item 48)	3.78	3.38-4.13	3.23	2.75-3.88
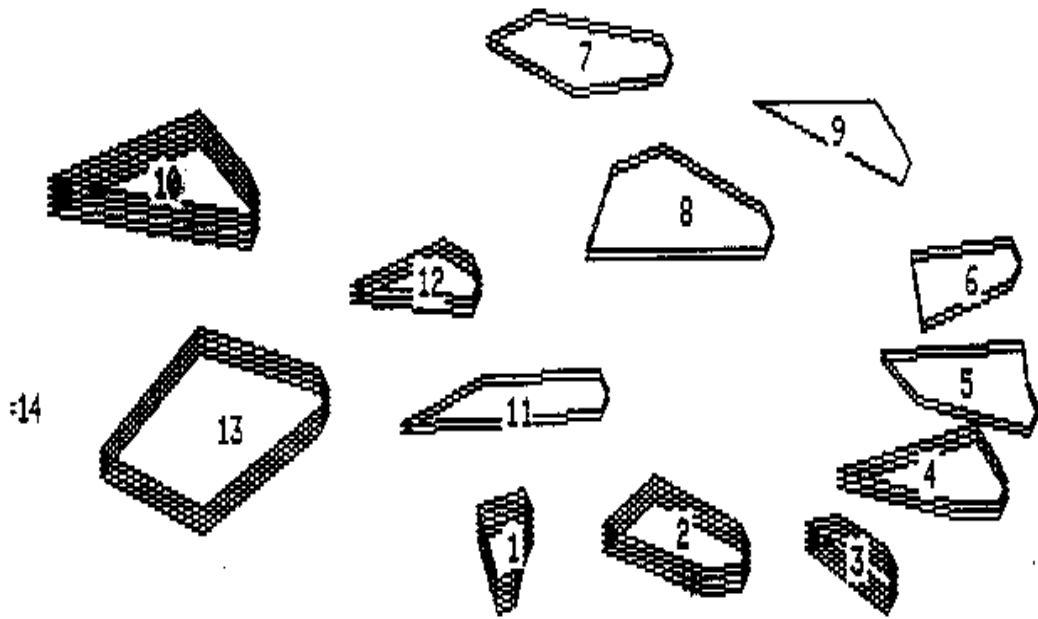
Ratings for 14 Cluster Solution
Stroke
Rehabilitation Hospital Staff

		Import. Outcome	Range for items	Import. Rehab.	Range for items
STROKE					
'Family' items of 1 and 2		4.50	4.14-5.0	3.65	3.33-4.0
Psycho-social adjust/accept items of: 1		4.43	4.29-4.57	3.76	3.71-3.86
	2	3.88	3.5-4.3	3.8	3.29-4.29
	3	4.14	3.43-4.71	3.19	2.57-3.71
Vocational/avocational (4 + it. 8)		3.85	3.57-4.29	3.77	3.43-4.0
Access: 5 (- item 8)		3.65	3.57-3.71	3.86	3.14-4.29
6 (+ items 32, 48)		3.8	3.57-4.0	3.57	3.29-3.86
Basic function (7 + it 54)		3.66	3.14-4.43	4.51	4.29-4.86
Outdoor/general mobility (9)		3.38	3.0-4.0	4.05	3.86-4.14
Communication (10 - it 17)		4.43	4.15-4.57	4.39	4.14-4.71
Confidence (11 + it 34)		3.75	3.29-4.57	3.68	3.29-4.14
Meaningful Activity (12)		4.0	3.71-4.29	4.06	3.71-4.43
Medical 13		4.06	3.43-4.57	4.06	3.71-4.43
14		3.79	3.71-3.86	3.93	3.46-4

Discussion of Results

Although the main purpose of the first stage is to develop an item pool and to make preliminary comparisons between the perceptions of different stakeholder groups, there are a number of interesting findings that have emerged from the groups with hospital staff. The maps can obviously be analysed in great depth. This section reports a few of the most striking findings.

Breadth of Perspective

Although we cannot claim that the ideas revealed in this study are representative of all or most rehabilitation hospital staff even these preliminary results provide much richer material for conceptualising outcomes than has usually been the case. Most of the content of traditional outcome measures is contained in two or three clusters on the 2 dimensional solution or three or four cells of the 3 dimensional matrix. On the other hand the models emphasise the importance of a sense of personal control and participation in valued social roles as closely associated with ultimate adjustment and acceptance and life satisfaction.

Traditional Dimensions

All of the groups identified a dimension on their maps equivalent to the traditional "function-feeling" dimension although the extreme of the function dimension was usually related to basic physical function. Function in social roles is in an intermediate position on both the two and three dimensional maps.

Views on Psychological Adjustment

There was considerable variation between the groups on the location of *psychological adjustment* items. For the head injury group these were clustered near the *self expression* items and are distant form the family items. For the stroke group *psychological adjustment* items are almost inextricably mixed with family and social items.

By contrast, for the back pain group, psychological adjustment items are intimately associated with medical and pain management issues. The two dimensional map would suggest an extreme medicalisation of the clients psychological state in the perceptions of these participants. This interpretation is strengthened by the observation that the back pain map has no centre. Generally in MDS maps the items at the centre are integrative and imply some sort of mixing of the peripheral items. The head injury and stroke groups have *self expression* and *meaningful activity* respectively at the centre; there is no equivalent cluster on the back pain map.

The three dimensional solution for the back pain group modifies this perception somewhat. There are a group of items at the centre of dimension 2 which suggest the theme of life satisfaction. None-the-less it appears that the idea of "meaning in life" is a less dominant principle for the back pain group than for the other two groups. This may be an appropriate variation given that these staff work primarily with outpatients whilst many more stroke and head injury patients are seen as inpatients. Another explanation may be that people with back pain are expected to return to something (work), whereas people after strokes or head injury may need to find new roles from which they can derive satisfaction. It will be important to compare these findings with the perspectives of other stakeholder groups

Future Stages of the Project

Methodological and practical issues related to the Concept Mapping process and follow up processes necessary to develop a comprehensive set of outcomes with wide stakeholder support, have been resolved to a great extent.

The next stage of the project involves two steps. First the concept mapping process will be conducted with client and caregiver groups as well as community based service providers using the standard methodology. Once a broad item pool has been developed this will be distributed to a wider group for sorting and rating in a mail survey format. This will allow more widely representative maps to be developed to establish and compare the structured conceptualisation of outcomes of different groups.

The third major stage of the study will involve following up a cohort of people eighteen to twenty four months after the onset of their disability in order to validate the outcomes and the conceptual frameworks that have emerged from the groups. A combination of relatively open interviews and appropriate standardised instruments will be used. Throughout the project it will be essential to establish collaborations with other treating centres and stakeholder organisations, in order to facilitate the development process and establish a wide commitment to the basic concepts.

TABLE

Key Elements of Overall Research Project

Research Question	Ideographic methods	Establishing generalisability	Key theoretical Issues

What are the important quality of life outcomes for different conditions?	• Concept maps with different stakeholder groups and different conditions at one site
	  • establish perceptions of different stakeholder groups
	  • structural analysis as well as cluster analysis to identify the ways groups differentiate outcomes
		• replication at one other site
		Sort and rate with a common item pool at a number of sites
			• examination of the issues linking objective and subjectice quality of life
			• consideration of ethical issues related to prescriptive norms

What are the important prerequisites for the attainment of these outcomes? (not just what mucks it up, ie a salutogenic[2] approach)	• focus groups and questionnaires on preconditions for outcomes using the capacities, opportunities, morale model • as above on what are the best indicators of a likely good/bad outcome at 1 month, 3 months, 1 year, 3 years lit review on same	• survey (? loosely a Delphi format) • publish for comment, establish wider ownership of project, newsletter, partnership projects etc.	• theories of processes of disablement and of quality of life construction • review of predictive studies related to long-term outcomes
What preconditional thresholds distinguish outcome groups?	• follow up study, retrospective, based on home visit, depth interviews and ? one or two standard instruments	adequate sample size replication at other sites develop a questionnaire from the local project	• review of empirically identified thresholds determining high quality outcomes
What important indicators of high quality outcomes can be applied to population groups (eg industries companies)?	• pilot surveys	• surveys and studies to establish norms	• theory of the function of indicators in accountability systems • consideration of utility and feasibility issues • servicing and maintaining an indicator system
How can this information best be used to improve practice (eg funding models, systems of performance indicators, identifying examples of best practise) etc.	• development and testing of pilot projects • support for the development and dissemination of examples of best practice	• dissemination projects	• application of theories of dissemination of innovations • development of evaluation methodologies suited to support flexible dissemination (emphasis on documenting the "lessons to be learned" and the conditions of success)

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[2] "Salutogenisis" is derived from greek roots meaning, the creation of well being (Antonovsky, 1987).

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