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‘User experiences of health and social care services’

Report Appendices

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APPENDIX 1 PROFORMAS

Reference	Irish Neurological Alliance 2000, *Standards of Care for People with Disabling (Progressive and Static) Neurological Conditions in the Hospital and Community*.	**Ref No**	NO.001
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Disabling (progressive and static) neurological conditions**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

Report is divided into (relevant) 'diagnostic, minimal impairment, moderate impairment and significant disability chapters. The aim is to set standards of care for most of the target groups covered (plus some others e.g. muscular dystrophy). The important points that relate directly to user experiences are:
Certain clear diagnosis and fast tracking through system
Rights to know diagnosis and standards for breaking news
Relevant voluntary support from organisations
Legal and entitlement advice
Discharge planning standards
Retraining and education
citizen's advice support
access to general practitioner and specialist expertise
co-operation between community support and hospital care
complaints procedures
access to services and equipment provision
specifications to be developed on what constitutes 'a good service'
information on suitable facilities (palliative care)
need for client centred plans
access to free healthcare (this is in Ireland)
transport issues
NB Also includes section on family carers and standards for them also.

Reference	Neurological Alliance of Ireland 2001, *Standards of Care for People with Non-Physically Disabling Neurological (and Associated Psychiatric) Conditions*	**Ref No**	NO.002
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Non-physically disabling neurological conditions**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

Report is divided into (relevant) 'diagnostic, minimal impairment, moderate impairment and significant disability chapters. The aim is to set standards of care for some of the target groups covered (e.g. epilepsy, headache/migraine, head injuries, autism, psychiatric conditions: psychosis, depression/mood disorders and obsessive compulsive disorders). The important points that relate directly to user experiences are
access to specialist services
explanation of diagnosis/ investigations from specialists, including support services
streamlined hospital/ community service interface
appropriate access to rehabilitation services/ long term care if appropriate
training to be given to junior staff on these standards
reasonable access to regular specialist review
treatments options to be offered and discussed
sexuality should be recognised, access to genetic counselling
medication in pregnancy issues
counselling/ treatment access in altered sexual functioning
educational and employment opportunities should be offered
re-entry into workforce issues should be considered
government sponsored public awareness to reduce stigma

Reference	Shah, S. & Priestley, M. 2001, *Better Services, Better Health: The healthcare experiences of Black and minority ethnic disabled people* Leeds Involvement Project, Leeds..	**Ref No**	NO.003
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 T2 T3 **T4**		
Location of study	**UK** Other		
Long Term Condition	**General (ethnic minority/disability)**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Wide variety of user views/experiences sought from respondents with a varied background of disabilities. However the focus of the study is on south Asian and afro-Caribbean individuals in Leeds and their experiences of doctors/hospitals.

4 key informants deemed to have 'expertise' as users and/or providers of health/social care contributed information. Group and individual interviews then took place (28 individuals in all) to generate user perspectives. (**important to note** here that the researchers recognise that user views were often mediated by translation from foreign/sign languages).

Users highlight cultural insensitivity across a range of services

Users highlight the way that the physical/built environment of many health/social care facilities restricts their mobility/access

Users highlight how they have organised their response via self-help groups

The summary provides action points derived from user experience/views

*****this report is recommended for its clear layout, use of illustrations, and availability via the web

Reference	Begum, N. 1996, "General Practitioners' role in shaping Disabled Women's Lives," in *Exploring the Divide*, C. Barnes & G. Mercer, eds., The Disability Press, Leeds.	**Ref No**	NO.004
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 T2 **T3** T4		
Location of study	**UK** Other		
Long Term Condition	**General**		

Key points relating to user's experiences/views of (health or social care) services

Aim: explore divide between Illness and Disability

A General Practitioner can be passport to whole range of services and support, therefore they can significantly influence the lives of disabled women.

Most common reasons for disabled women contacting GP is for repeat prescriptions, medical reports and authorisation to use other services.

Disabled women less likely to contact GP for women's health matters.

GPs' prejudices and low expectations of disabled women influence the type of support that is provided, may lead to being cut off benefits.

Disabled women are no more susceptible to illness than non-disabled women.

Relationship between illness and impairment is complex: for some disabled women impairments are not a medical problem, but others are more vulnerable to illness because of their impairments.

GPs did not believe disabled women had impairments therefore diagnosis and intervention often inappropriate (e.g. woman with arthritis was labelled neurotic and admitted to psychiatric hospital)

GPs reluctant to acknowledge disabled women's need for women's health services (a feeling that GPs view disabled women as disabled first)

GPs try to prevent disabled women from having children, not support them to make informed decisions and choice. Uses sterilisation for women with learning difficulties

Need to include disabled women in discussions about women's health, primary health care and disabled people's use of health services.

Reference	Clark, L. 2002, Liverpool Central Primary Care Trust Accessible Health Information: Project Report Liverpool Central Primary Care Trust, Liverpool.	**Ref No**	NO.005

Research methods	Quantitative	Qualitative	**Mixed**	Other
Typology	T1	T2	T3	**T4**
Location of study	**UK**		Other	
Long Term Condition	**General**			
Confidence Rating	**High**	Medium	Low	

Key points to user's experiences/views of (health or social care) services

Highlights users' perceptions and experiences of information provision within NHS

Reviews national studies and local research projects documenting experiences of disabled people

Particular strength is study of women's experience of information provision following cervical screening programmes

Contains important recommendations for provision of accessible information in the NHS

Reference	Zarb, G. 1992, *Ageing with Polio* University of Greenwich, London	**Ref No**	NO.006
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Polio**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

User views/experiences gathered from 65 individuals. 29 followed up with in-depth interviews where themes were identified across a spectrum of issues relating to the disease process.

Extensive presentation of individual narratives from interview transcripts highlight a subjective response to a wide variety of personal/social circumstances.

Numerical tables list participants in % by gender, race, impairment and longevity of condition

User experience identifies areas where the health/social services need to respond better to ageing issues

The breadth and depth of user views/experiences elicited could be used to begin a variety of small scale research topics

In the section on health services/health care provision the user views are supplemented by a short editorial commentary that suggests a lack of professional understanding of the subject

User views indicate a lack of co-ordinated response to polio related issues, particularly ageing. This suggests a clear need for one governing agency to direct future research.

The willingness of users to air their views and share their experiences highlights the potential of such exercises to produce very useful data.

Reference	Zarb, G. 1992, *Ageing with Multiple Sclerosis* University of Greenwich, London	**Ref No**	NO.007
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	Medium - Unnecessary use of full transcripts. Could use single quotes to illustrate findings		

Key points relating to user's experiences/views of (health or social care) services

Aim: Examine practical impact of aging, and experiences of disability. Cannot examine the practical implications of ageing without noting what influence ageing with a disability has on people's lives

Main Issues:

Respondents felt their needs and existence had been overlooked

Often difficult for older disabled people to accept they need and, ask for help because they are experts in the art of their own survival.

Long periods of isolated could mean older disabled people often are unable to get their needs recognized by others or the confidence to articulate their needs.

Particularly the case for older disabled women

Older disabled people from Black and ethnic minority communities were isolated. Most had no access to support and advice offered by established disability organizations.

This is supported by Shah and Priestley (2001) Health care experiences of Black and minority ethnic disabled people. Such a conclusion is indicated by the fact that less than 3% of the original study sample, drawn from disability organizations, were from ethnic minority communities.

Several respondents felt concerned about losing independence, physical, personal and wider control over their lives in Terms of how they wished to live.

Reference	*Zarb, G. 1992,* Ageing with Parkinson's Disease *University of Greenwich, London.*	**Ref No**	NO.008	
Research methods	Quantitative	**Qualitative**	Mixed	Other
Typology	T1	**T2**	T3	T4
Location of study	**UK**	Other		
Long Term Condition	**Parkinson’s Disease**			
Confidence Rating	High	**Medium**	Low	

Key points to user’s experiences/views of (health or social care) services
Highlights users’ experiences of ageing among people with Parkinson’s disease

Documents experiences of ‘carers’ for the target group

Explores practical and personal support needs – domestic assistance, transport, housing, and financial. Also considers their views on Parkinson’s Disease Society and its role.

Reference	Richman, J. A., Jason, L. A., Taylor, R. R., & Jahn, S. C. 2000, "Feminist Perspectives on the Social Construction of Chronic Fatigue Syndrome", *Health Care for Women International*, vol. 21, no. 3, pp. 173-185.	**Ref No**	NO.009
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**General (chronic fatigue syndrome)**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

This is a highly theoretical paper that offers a feminist deconstruction of CFS.

One individual reports that they don't believe there is any link with depression while another didn't feel supported by their doctor. That apart there is no user perspective.

Reference	Gordon, P. A., Winter, R., Feldman, D., & Dimick, K. 1996, "Group Work for Persons with Multiple Sclerosis", *Journal for Specialists in Group Work*, vol. 21, no. 4, pp. 243-251.	**Ref No**	NO.013
Research methods	Quantitative **Qualitative** Mixed Other But not really a report of research		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other (US)**		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	High Medium **Low N/A**		

Key points relating to user's experiences/views of (health or social care) services

One psycho-educational group is described (a case study) but the reported concerns of people in the group are more about everyday life and how they are treated by the public in general rather than health and social care services specifically.

Principally the paper aims to provide professionals who employ group techniques with information about the experience of MS so that they can run groups in an informed way (Given that user studies often complain that professionals have no expert knowledge about their specific condition, this seems like a good plan.)

This paper contains the kind of information professionals (who want to use group work) ought to have about the experience of MS. Presumably, knowing this, professionals may behave differently but this is not the same as reporting user views.

Reference	McLaughlin, J. & Zeeberg, I. 1993, "Self-Care and Multiple Sclerosis: A View from Two Cultures", *Social Science and Medicine*, vol. 37, no. 3, pp. 315-329.		**Ref No**	NO.014
Research methods	Quantitative	**Qualitative**	Mixed	Other
Typology	T1	**T2**	T3	T4
Location of study	UK		**Other**	
Long Term Condition	**Multiple Sclerosis**			
Confidence Rating	**High**	Medium	Low	

Key points relating to user's experiences/views of (health or social care) services

- Article is about the role of self-care in multiple sclerosis and is an international comparison study (Denmark and USA). Authors compared and contrasted self-care practices of 51 Danish and 35 American people with MS at various levels of disability. Respondents were asked about ways they managed their symptoms and problems during periods of non-medical contact – including methods of following the medical regimen, alternative treatments, use of lay-referral systems and sources of information regarding physical, psychological, social and environmental dimensions of coping with the illness.
- The two groups varied regarding adaptation strategies and primary sources of information used.
- Their ultimate aims were similar – to gain control over uncertainty, dependency and physical and emotional decline.
- Study suggests that the empowering role of self-initiated self-care strategies in chronic illness may transcend differences in health care systems.

Reference	*Rea, C. A. & Rea, D. M. 2000, "Responding to user views of service performance",* Journal of Mental Health*, vol. 9, no. 4, pp. 351-363.*	**Ref No**	NO.015
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 T2 T3 **T4**		
Location of study	**UK** Other		
Long Term Condition	**Mental Health Users (General)**		
Confidence Rating	**High** Medium Low		

Key points to user's experiences/views of (health or social care) services

Notes different ways of assessing and integrating user views (and often use of inappropriate service performance measures from user standpoint)

Stresses importance of going beyond measures of clinical effectiveness and inclusion of mental health users' voice in service planning and delivery

Emphasises importance of user validation but highlights limited dissemination of user survey findings or evidence that their views have been taken seriously

Reference	Willner, L. & Dunning, D. 1993, *Ageing with Cerebral Palsy* SCOPE, London.	**Ref No**	NO.016
Research methods	Quantitative **Qualitative** Mixed Other Depth interviews with 65 adults – analytic quota sample		
Typology	**T1** T2 T3 T4 If you count Scope as one such		
Location of study	**UK** Other		
Long Term Condition	**Cerebral Palsy**		
Confidence Rating	**High** Medium Low Except its more than 10 years old, but it did focus on adults with cerebral palsy and reporting their views		

Key points relating to user's experiences/views of (health or social care) services

A number expressed a wish to have had, or to have, access to emotional support, counselling or psychotherapy at some point. The few who had experienced psychotherapy had found this helpful.

Emotional needs of their parents and siblings often not recognised also.

Various experiences of education training and employment, some reports of dissatisfaction with schools and discrimination in employment. Fewer than 30% were in employment (94% under retirement age)

Professionals insufficiently familiar with their particular condition – they should be kept better informed

Most people quite satisfied with regular GP. Most cases of insensitive or unsatisfactory medical treatment related to experiences in hospital, although 2/3 had not seen a consultant in the last 5 years. Re hospital – majority of doctors and nurses perceived as sympathetic – dissatisfaction in a (significant) minority of cases.

Although aging (getting older in general) brought an increase in physical problems (and this seemed to be at an earlier point than in the general population), even so few people visit GP for regular checks and the majority had not seen a consultant or physiotherapist for at least five years. For many this was because they had given up on the idea that they could get treatment which would help. (the kind of experiences were: half of those who experienced spasms reported that these had intensified; more than half described increasing difficulties with mobility (most of these were under 60); one third described increases in pain.) Some anxiety about the future, particularly assoc with physical deterioration.

In general people were happy with dental treatment though some had taken a while to find the right practitioner

Length of time taken to obtain home equipment and adaptations often too long

About half had social work contact and these divided about equally into those who commented favourably on their assistance and those who commented unfavourably.

40% had OT contact and favourable/unfavourable comments ratio was 2.5/1, leaving aside equipment delays as above.

2/3 used a wheelchair. Calls for design improvements in manual and electric wheelchairs.

Lack of help with gardening a serious problem for some.

Financial costs associated with disability a concern (volunteered by respondents as no questioning about it)

Half said they didn’t need any more support than they got, 1/5 wanted more home help; 1/10 would like to go out more. 1/10 complained of social isolation

Majority believed that societal attitudes to impairment have improved, particularly among younger people.

Reference	Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M., & Beecham, J. 2002, "The Quality of Life of People 12 Years after Resettlement from Long Stay Hospitals: user's views on their living environment, daily activities and future aspirations", *Disability & Society*, vol. 17, no. 7, pp. 741-758.	**Ref No**	NO.019
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 T2 T3 **T4**		
Location of study	**UK** Other		
Long Term Condition	**General (learning difficulty and mental health)**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Positive and negative user experiences of quality of life issues are displayed by % figures in tables and by extensive direct quotations

The authors note that due to their circumstances some respondents may have felt inhibited not only by the process but also by the potential to be branded as 'trouble-makers' hence levels of dissatisfaction may be artificially low. Methodological implications for future study.

User views of quality of life issues regarding concrete experiences were easily ascertained. Thoughts on abstract concepts and future care were not.

By insisting on user experience the study reports on quality of life from a subjective, rather than a professional/service perspective. Validity and confidence rating high.

Overall positive responses from users confirm the value of current policy and point to future directions

Negative responses indicate areas where professional/service providers can intervene to make improvements

Authors note that side-effects of medication prevented some respondents from contributing as much as they may have wished

Worthwhile references to pursue may include:-

Holland, A., Meddis, R. (1997) People living in community homes: their views *British Journal of Learning Disabilities* 25, pp. 68-72

Cambridge, P. *et al* (eds.) (2001) *Twelve Years On: the outcomes and costs of community care for people with learning disabilities and mental health problems: a report to the Department of Health*

Canterbury: Tizard Centre

Reference	*Preston-Shoot, M. 2001, "A Triumph of Hope over Experience? Modernizing Accountability: The Case of Complaints Procedures in Community Care",* Social Policy & Administration, *vol. 35, no. 6, pp. 701-715.*	**Ref No**	NO.020	
Research methods	Quantitative	Qualitative	Mixed	**Other**
Typology	T1	T2	T3	**T4**
Location of study	**UK**	Other		
Long Term Condition	**General**			
Confidence Rating	High	**Medium**	Low	

Key points to user's experiences/views of (health or social care) services

Review of four studies of impact of complaints procedures as a way of assessing user views/ redress

Explores how far users empowered to speak out against local management/ professional agendas and cultures.

Users often inhibited by prospect of going down the 'complaints' path, and organisational hostility to staff 'whistleblowers'

Overall conclusion that complaints procedures have had little impact in effecting service changes desired by users

Reference	Pooley, C. G., Gerrard, C., Hollis, S., Morton, S., & Astbury, J. 2001, "'Oh it's a wonderful practice...you can talk to them': a qualitative study of patients' and health professionals' views on the management of type 2 diabetes", *Health & Social Care in the Community*, vol. 9, no. 5, pp. 318-326.	**Ref No**	NO.021

Research methods	Qualitative (Used in article), whole study used mixed methods			
Typology	T1	T2	T3	**T4**
Location of study	**UK**			
Long Term Condition	**General**			
Confidence Rating	**Medium** (could be replicated with other health authorities in other parts of the country)			

Key points relating to user's experiences/views of (health or social care) services

Paper centres around 5 themes which were identified, through qualitative analysis, as important to the effective management of diabetes types 2, and can provide a framework for future related research.

5 key themes: *Time, Continuity [of care], Questioning [patients asking questions to practitioners], listening, individuality [experiences of living with diabetes]*

KEY REFS:

Previous research show that lack of common objectives and the poor communication between patients and health professionals can influence ineffective diabetes management (see *Hares et al, 1992; Bennett, 1983; Caspari & van der Waal, 1995; Cohen, 1994)*

Other studies found that health beliefs and social support are the most consistent and strongest predictors of effective self-care *(Wilson et al, 1986)* and patients who are more involved in decision making about their illness are most likely to achieve effective diabetes management *(Peyrot & Rubin, 1994; Maillet et al, 1996)*

Key Conclusions:

Patients and practitioners highlight same concerns, and identify similar problems in delivery of diabetes care.

Patients and practitioners both feel the underlying problem causing ineffective management of diabetes relates to issues of TIME. Lack of time fragments care, leads to inadequate consultations, prevents health professionals from adequately listening to patients and addressing their individual needs.

Patients accept that effective delivery of diabetes care is primarily their responsibility.

Patient self-management can only work if patients are not disempowered by the constraints of the structures within which care is delivered.

Refs:

Bennet I (1994); Do doctors address the concerns of patients with diabetes?; *Diabetic Medicine;* Vol. 11; pp586-589

Caspari & van der Waal M (1995); Differences in preferences between diabetic patients and diabetologists regarding quality of care: a matter of continuity and efficiency of care; *Diabetic Medicine;* Vol.12; pp828-832

Cohen et al (1994); Explanatory models of diabetes: patient-practitioner variation; *Social Science and Medicine;* Vol. 38; pp59-66

Hares et al (1992); Diabetes care: who are the experts; *Quality in Health Care;* Vol. 1; pp219-226

Maillet et al (1996); Using focus groups to characterize the health beliefs and practises of black women with non-insulin dependent diabetes; *Diabetes Educator;* Vol. 22; pp39-46

Peyrot M & Rubin R (1994); Structure and correlates of diabetes specific locus of control; *Diabetes Care;* Vol. 17; pp994-1001

Reference	Solas, J. 1995, "Recovering and reconstructing the client's story in social work", *Australian Social Work*, vol. 48, no. 3, pp. 33-36.	**Ref No**	NO.023
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 T2 T3 **T4**		
Location of study	**UK** Other		
Long Term Condition	**General**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Shows importance, for social workers, to listen to clients' stories/ narrative and use this as a means of reviewing their past, help sort out their present and how they can be better in the future.

There is a need to move away from the traditional model of social work interviews, asking client a series of questions driven by the interviewers theory and practice wisdom. Need to remove emphasis on coherence, continuity and closure, even in narrative interviews because clients' story is polymorphic, divided & discontinuous
When social work practitioners are interviewing clients, they need to consider the following:
Clients' life stories do not come as well-ordered points - not naturally coherent, continuous and closed
Coherence, continuity and closure can only be achieved through omission and selection – lose clients' whole story
Practitioners who attempt to pursue a concordant narrative are motivated by the idea that the client and themselves represent and construe the world and their experience in it as ordered and unified
If the world and lived experience is presented in a coherent, continuous and closed way, there is a danger of normalising the client-narrator (Foucalt, 1954)
Good social work interviews would be to encourage clients to explore the ways in which their problems/ illness influenced their lives, sometimes talking about instances discordant with the primary issue. This is more helpful to the client than answering ordered questions about their illness, Internalising problematic descriptions of themselves which only leaves the client feeling trapped with no way out.
Client needs to be the author of their own story
Points of contradiction and discontinuity identified by clients in their stories can evolve into Success stories (Goffman, 1961)
Storytelling/ narrative can help clients to consider different versions of reality and decide which is more important to them

References:
Goffman E (1961); *Asylums: Essays in the social situation of mental patients and other inmates*; New York: Doubleday
Foucalt M (1954); *Mental illness and psychology*; A Sheridan Trans; University of California Press

Reference	Luanaigh, P. O. 2002, "Views held by service users and colleagues of health visitor provision", *Community Practitioner*, vol. 75, no. 4, pp. 139-141.	**Ref No**	NO.024
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 T2 T3 **T4**		
Location of study	**UK** Other		
Long Term Condition	**General**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

A very small survey of user attitudes to health visitor services. The sample size, 50% response rate and rural practice area reduce confidence in the findings. Users indicate…..

The service is rated more highly by contemporary mothers than by other groupings
Users expect to be able to receive advice on a broad range of health related issues
Users tended not to seek advice on financial or psychological aspects of health care.

Reference	Johnson, L. 1995, *Getting the message: users' and carers' experiences of community care in Leeds* Leeds Community Health Council, Leeds.	**Ref No**	NO.028
Research methods	Quantitative **Qualitative** Mixed Other In-depth, loosely structured interviews with 50+ users and carers		
Typology	T1 T2 T3 **T4**		
Location of study	**UK** Other		
Long Term Condition	**Not specified**		
Confidence Rating	**High** Medium Low The research appears methodologically rigorous. The findings are generalisable and although somewhat dated retain pertinent recommendations (that would probably be replicated if similar research was carried out now.		

Key points relating to user's experiences/views of (health or social care) services

The research was undertaken in Leeds between 1994-5 in the wake of the 1993 implementation of the NHS & CC Act which emphasised identifying individual needs and providing services tailored to those needs.

Key recommendations arising from the research:
Information particularly about the system and its processes, without this users will continue only to access services at times of crises and their ability to participate in decisions remain limited.
A range of recommendations were made about domiciliary & day services and residential & nursing home care. These can be generalised as being related to increased service versatility and timeliness, greater user involvement in decision making and improved training for staff to ensure they hear and act upon the wishes of service users

Reference	Buchanan, K. M., Elias, L. J., & Goplen, G. B. 2000, "Differing perspectives on outcome after subarachnoid hemorrhage: The patient, the relative, the neurosurgeon", *Neurosurgery*, vol. 46, no. 4, pp. 831-838.	**Ref No**	NO.030
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Brain Injury (Subarachnoid Haemorrhage (SAH))**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Patients and family members were not asked to talk about or assess health/social services.

Research with patients and family members concerning neurobehavioural changes (including changes in personality, behaviours, employment, social roles, social contact, sexuality), psychological distress and 'family burden' (semi-structured interviews and use of scales) following surgery for SAH (12 to 32 months after surgery).

Patients and family members were interviewed separately, to compare the patients' assessments with those of family members and vice versa.

It was found that neurosurgeons had over-stated the degree of recovery and normal functioning in patients when comparisons were made with patient and family members' own evaluations.

Reference	Prigatano, G. P. 2000, "Neuropsychology, the patient's experience, and the political forces within our field", *Archives of Clinical Neuropsychology*, vol. 15, no. 1, pp. 71-82..	**Ref No**	NO.031
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Brain injury**		
Confidence Rating	High **Medium** (expert opinion piece) Low		

Key points relating to user's experiences/views of (health or social care) services

No newly gathered data on users' service experience is presented. Rather, the author reflects on clinical work with patients, and thus is reporting on patients' experiences as he has observed them.

The key observation is that patients can be non-cooperative and unhappy if they feel that the clinician has no interest in the patient's own account of their condition/life experiences.

The paper is based on a conference speech given by a leading clinical neuropsychologist, to others in his profession, in which the case is made for finding out about the patient's experience of neuropsychological assessments and treatments. This is presented as something that the profession has had no interest in, and that this is detrimental, not least because patients may not pay for treatments (USA).

Reference	Hubert, J. 1995, *Life After Head Injury* Ashgate, Aldershot.	**Ref No**	NO.032
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Severe Head Injury/Brain Injury**		
Confidence Rating	High Medium **Low***		

Key points relating to user's experiences/views of (health or social care) services

***** not enough information, very small sample (20)

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Inadequate standards of care on general wards of hospitals – less attention on patients; staff felt to have little knowledge of head injury.

Medical language not explained

Lack of information/communication about what was happening; information may have been given(e.g. at the beginning), but parents too shocked to absorb it. Did not know who to ask and/or how information from different people all fitted together.

Specialist hospital social workers, or psychologists, found to be patient and helpful; less likely to get a hotchpotch of individual opinions.

Transition from intensive care → a general ward seen as too sudden, and the difference in care and attention too extreme.

Inadequate service provision on return home

Problems in transport to rehabilitation or day centres; lack of co-ordination between hospitals in different Health Districts between Health and Social Services departments, and between Social Services departments in different areas – confusion!; problems in organising aids and adaptations; services (e.g. P/T; O/T; S/T) may drop off, even if level of need seems the same; lack of information/confusion re who is responsible for what service provision; feeling that consultants and rehab team relinquish responsibility once the patient goes home.

Sense of isolation from professionals/no effective consultation.

An unmet need for someone to talk to experienced in head injury and its consequences/counsellor/listening ear.

Some found the Headway Centres a valuable source of practical help and advice.

Main problem in aftermath of severe head injury was lack of adequate information, advice and support; someone to talk to from the beginning.

Local social workers very valuable in context of practical issues (e.g. arranging day care; helping to complete benefit claim forms), but often unable to respond to the more complex individual and familial problems that developed in aftermath of S.H.J as often did not have much experience in this area.

Reference	Bewley, C. & Glendinning, C. 1994, "Representing the views of disabled people in community care planning", *Disability & Society* , vol. 9, no. 3, pp. 301-314.	**Ref No**	NO.034
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	T1 T2 T3 **T4**		
Location of study	**UK** Other		
Long Term Condition	**General**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

Does not deal directly with user experience

A political discussion on the representation of disabled people win the service planning process. The authors find that disabled people may be disadvantaged by the reliance on written English as a medium for communication.

Despite the need for consultation the authors find that bureaucracy conspires against genuine representation by

Diluting contributions by insisting on giving every one a chance to speak

Asking for consultation on absolutely everything

Citing resource deficiencies

The authors also note a tendency by authorities to introduce 'a token disabled person' who is part of the planning team thereby giving this person a conflict of interest.

References

Was this article used in this project?

Beresford, P., Campbell, J. (1994) 'Disabled People, Service Users, User Involvement and Representation' *Disability & Society* vol.9, no. 4

Reference	Niemeier, J. P. & Burnett, D. M. 2001, "No such thing as 'uncomplicated bereavement' for patients in rehabilitation", *Disability and Rehabilitation*, vol. 23, no. 15, pp. 645-653.	**Ref No**	NO.038
Research methods	Quantitative Qualitative Mixed **Other√** (Literature review)		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Disabled people in rehabilitation (in general)**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

This paper does not consider rehabilitation patients' experiences/views of services.

It reviews the literature on the extent and nature of patients' bereavement associated with the loss of limb or function through accident, injury or the worsening of a degenerative condition.

The limitations of 'stages' or 'phases' theories of the grieving process are noted.

Guidelines are offered on assessing patients in rehabilitative contexts.

Reference	Cusick, C. P., Brooks, C. A., & Whiteneck, G. G. 2001, "The use of proxies in community integration research", *Archives of Physical Medicine and Rehabilitation*, vol. 82, no. 8, pp. 1018-1024.	**Ref No**	NO.039
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Covers a range of conditions, including MS, spinal chord injury, brain injury.**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

This paper does not provide information on users' experiences of services.

The research reported concerned levels of agreement between disabled people and proxies ('participant-proxy agreement') with regard to measures of community integration.

A number of measurement scales are used. The key result is that proxies are found to provide data comparable to people with disabilities. Proxy data has high reliability.

Reference	Mohr, D. C., Boudewyn, A. C., Likosky, W., Levine, E., & Goodkin, D. E. 2001, "Injectable medication for the treatment of multiple sclerosis: The influence of self-efficacy expectations and injection anxiety on adherence and ability to self-inject", *Annals of Behavioral Medicine*, vol. 23, no. 2, pp. 125-132.	**Ref No**	NO.040
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 T2 T3 **T4**		
Location of study	UK **Other**		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Patients are increasingly obliged to manage injectable medications themselves.
Interferon beta-la recommended for the treatment of MS must be injected intramuscularly on a weekly basis. Patients generally taught how to self-inject
Longitudinal study examined cognitive and affective contributions to the ability to self-inject and adherence to drug regime over 6 months following initiation
Participants were 101 patients with a relapsing form of MS.
Injection self-efficacy expectations, injection anxiety, adherence expectations, method of injection administration and 6 month adherence to drug regime were fitted to a path analytic model.
Pre-treatment injection self-efficacy expectations were significantly related to 6-month adherence. This relation was mediated by the patient's ability to self-inject.
Patients' experienced level of injection anxiety was related to adherence but not to method of injection.

Reference	Mohr, D. C., Dick, L. P., Russo, D., Likosky, W., Pinn, J., Boudewyn, A. C., & Goodkin, D. E. 1999, "The psychosocial impact of multiple sclerosis: Exploring the patient's perspective", *Health Psychology*, vol. 18, no. 4, pp. 376-382.	**Ref No**	NO.042
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

This paper examines the psychosocial impact of MS, from the patient's point of view, but <u>does not</u> touch on patients' experiences/views of services.

Qualitative research with patients was undertaken to generate statements about the impact on life and wellbeing of living with MS. These statements (67) were then presented to a telephone sample of patients for rating (Likert scale). A range of scales were also administered to establish physical functioning, cognitive impairment, depression and anxiety, coping. Psychosocial effects were divided into three categories: Demoralization, Deterioration in Relationships, and Benefit-Finding (i.e. beneficial psychosocial outcomes). The finding reported as surprising by the researchers was that a proportion of patients indicated that there were some benefits from having MS.

Reference	OCallaghan, C. C. 1996, "Lyrical themes in songs written by palliative care patients", *Journal of Music Therapy*, vol. 33, no. 2, pp. 74-92.	**Ref No**	NO.044
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**General (palliative care)**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

User experience is not referred to anywhere in the article. This is the sort of thing that gets qualitative research a bad name.

Reference	Barnes, M. P. & Skeil, D. A. 1996, "Outpatients in neurological rehabilitation", *International Journal of Rehabilitation Research*, vol. 19, no. 1, pp. 39-45.	**Ref No**	NO.045
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Multiple sclerosis**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

User views and experiences of attending a neurological out-patient clinic have been canvassed by questionnaire

Views and experiences on the clinic format have been addressed and practice changed according to accommodate expressed preferences. In rank order these were found to be:

A preference for a 'drop-in' system
Seeing just one or two professionals with relevant expertise
A doctor based clinic with referral onwards to appropriate therapists
To see relevant therapists individually rather than as part of a multi-disciplinary group*
To see all doctors and therapists together at the same time*

* the contradiction apparent in the last two choices reveals the impossibility of keeping all
of the people happy all of the time

Reference	Perks, B. A., Mackintosh, R., Stewart C.P.U., & BARDSLEY, G. I. 1994, "A survey of marginal wheelchair users", *Journal of Rehabilitation Research and Development*, vol. 31, no. 4, pp. 297-302.	**Ref No**	NO.046
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 T2 **T3** T4		
Location of study	**UK** Other		
Long Term Condition	**Multiple Sclerosis (modal diagnosis)**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

This is a survey of marginal wheelchair users which encompassed all wheelchair users in Tayside, Scotland about their wheelchair propelling experiences. Marginal wheelchair users represent 15% of the total wheelchair using population. 80 people surveyed (44 male, 36 female). Modal diagnosis was multiple sclerosis (26.3%) but the study covered many other LTC e.g. muscular dystrophy (5%) , rheumatoid arthritis (8.8%) and cerebral palsy (7.5%) as well as paraplegia (7.5%) amputees (6.3%) CVA (6.3%) and a catch-all category that includes brain lesion, brittle bones, cervical spondilosis, Freidrich's ataxia, spastic paraplegia, hydrocephalus, polio, quadriplegia and TB spine (approx. 2.5% each). 24% (19) came from 0-30 age group, 50% (40) between 30 and 60 years, 26% (21) in the 60-90 age group. Results indicate:

75% (60) were using standard Ministry model 8 wheelchairs – remaining 25% using alternative models.

67% (40) claimed their Model 8 wheelchair is inadequate and 35% (7) of the alternatives did also.

33% (20) claimed technical problems and 42% (25) 'general discomfort'

Nearly two thirds (65%,52) did not live in purpose-built wheelchair housing which lead to propulsion difficulties caused by environmental factors. The y people faced both indoor and outdoor access problems.

Functional deterioration in middle age (due to e.g. MS) (30-60 years)

Frailty due to old age creates propulsion problems for established wheelchair users (26% are in the 60-90 age group).

The majority (59%) of users questioned said that heir wheelchairs were inadequate for their requirements. Problems included inadequate wheel positions (11%) castor wheels too small (18%) high rolling resistance (16%) obtrusive footplates (11%) and unsatisfactory handrims (6%).

Reference	Brown, J., Lattimer, V., & and Tudbal, T. 2003, *Provision of care in Motor Neurone Disease: An Investigation in Hampshire, Dorset and Wiltshire.* University of Southampton, Southampton.	**Ref No**	NO.047
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Motor Neurone Disease**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Note user/carer needs conflated in some of this publication. Following are noted as important to user/carers: 20 interviews; 11 users and 9 carers conducted

Continuity of care personnel

Fast track referrals to paramedical personnel

Equipment availability and timely delivery

Named key workers

Palliative symptom management

Report also highlights

Paucity of information on MND at national level (e.g. no MND databases in England)

Low numbers of people with MND (incidence and prevalence) – this means dedicated sole service provision is often difficult to procure (suggests that organising services with other LTC such as MS and PD, stroke may assist)

- MND diagnosis should drive concepts such as speed, specialised equipment and early referrals to paramedical professionals and palliative care providers – too often this is not the case.
- Limited co-ordination of services (health and social care)
- System does not accommodate speedy progression of disease to action personnel and equipment
- Limited knowledge of MND amongst the professions. Knowledgeable key workers required
- Lack of respite and long term facilities (particularly for those people who are not in the elderly group).
- Genuineness of staff viewed positively and appreciated
- MNDA praised for being most supportive, assisting with information, equipment and speeding up service delivery. Regional care advisors and branch volunteers valued.

Equipment availability – real problems with speed of disease progression – nearly always too late to be of use

Reference	Ellis, N., Upton, D., & Thompson, P. 2000, "Epilepsy and the family: a review of current literature", *Seizure*, vol. 9, no. 1, pp. 22-30.	**Ref No**	NO.048
Research methods	Quantitative Qualitative Mixed **Other Lit Rev**		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Epilepsy**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

The paper reviews the literature on the psychological well-being of family members when a child or adult has epilepsy. It does not claim to be a systematic review.

The paper <u>does not</u> address user's experiences of heath and social care service, its focus being on:

Parental responses to a child with epilepsy (distress, psychological morbidity).

Siblings psychosocial response to a brother/sister with epilepsy.

Increased levels of anxiety, depression and somatic complaints are found amongst family members.

It is noted that families need information and advice about epilepsy but that this is not usually volunteered by health services.

Clinical interventions (including educational packages) designed to alter behaviours and attitudes of family members are seen as necessary.

Innovations in research on the impact on family members of epilepsy is proposed.

Reference	Andrewes, D., Camp, K., Kilpatrick, C., & Cook, M. 1999, "The assessment and treatment of concerns and anxiety in patients undergoing presurgical monitoring for epilepsy", *Epilepsia*, vol. 40, no. 11, pp. 1535-1542.	**Ref No**	NO.049
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Epilepsy**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Study (RCT) investigating the impact of a treatment information package on patients being monitored for possible surgical treatment. Use of psychometric scales.

No information is supplied on patients' evaluation of services.

Outcome: patients in the 'high-information' group showed a significant decrease in anxiety and depression levels compared with those in the 'low-information' group.

Distinctions are made between the coping styles of patients: those that seek out information ('monitors'), those that avoid it ('blunters').

Reference	Raty, L., Hamrin, E., & Soderfeldt, B. 1999, "Quality of life in newly-debuted epilepsy. An empirical study", *Acta Neurologica Scandinavica*, vol. 100, no. 4, pp. 221-226.	**Ref No**	NO.050
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other** - Sweden		
Long Term Condition	**Epilepsy**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

Aim: Test Quality of Life Index to measure quality of life of epilepsy population to illuminate their quality of life

Epilepsy teams [made up of doctors, nurses, almoner, psychologists] have been established , in neurological clinics, to improve the quality of life of adults with epilepsy **–** helps patients with information, has conversations, organises patient gatherings
Higher quality of life score for patients with regular contact with epilepsy teams, but more side-effects of drugs
Lack of previous research on quality of life of patients with newly debuted epilepsy
Men had higher quality of life than women . Differences in socioeconomic area, and some in psychological/ spiritual domain
M/W felt most important factors to quality of life =: leisure activities; relationship with spouse; feeling of energy for daily activities; possibilities for a happy old age
High quality of life related to: satisfaction with personal goals; personal health; control over own life; work and leisure activities
Negative relation between frequency of seizures and quality of life in all domains but Family → low self esteem, tiredness, lack of concentration, anxiety
Highest quality of life related to Family: maintained self-esteem and relationship not disturbed by seizure frequency or side-effects of drugs
Lowest quality of life score related to Psychological/spiritual domain
Patients with low quality of life felt epilepsy dominated their lives → negative experiences of the change in life situation

Reference	Northern and Yorkshire Regional Council of Community Health Councils 1995, *Survey of spinal cord injured patients treated at Pinderfields Hospital and discharged into their local community: Summary Report and Recommendations of the Regional Council*.	**Ref No**	NO.051
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Spinal Cord Injury**		
Confidence Rating	High Medium **Low ***		

Key points relating to user's experiences/views of (health or social care) services

This study related to patients' experiences of Pinderfields Spinal Injuries Unit (SIU).

$^{2}/_{3}$ felt they had been given enough info while patients in the SIU; $^{1}/_{3}$ of respondents felt there had not been enough.

One half of respondents (n=78) reported their partners had not been given any support whilst they were patients in SIU.

Majority said satisfied or very satisfied with nursing care.

Majority reported generally satisfied with P/T service provided at the SIU.

Majority said generally satisfied with facilities provided at SIU.

Significant number dissatisfied with; food served at SIU; level of noise; amount of individual space, call buttons.

Vast majority generally satisfied with the daily routine and regime at the SIU.

A few people complained about being woken early in the morning and the very restricted visiting times.

Majority with a partner at time of injury reported that they were not given an opportunity to discuss with hospital staff how their injury would affect their sexual relationship .

Vast majority with children said SIU staff did not give them advice on: how to look after their children, how to help their children come to terms with the injury.

Over $^{2}/_{3}$ reported that not given any general health info on matters such as smoking, alcohol and diet.

Majority satisfied with their GP, district nurse, community P/T, home carer or paid care attendant.

***** not enough info given to judge; majority of sample discharges more than 2 years before survey undertaken.

Reference	*Pegg, R. 1992, "I am a being, not an illness",* Therapy Weekly, *vol. August 13, p. 4.*	**Ref No**	NO.052
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Motor Neurone Disease**		
Confidence Rating	High Medium **Low**		

Key points to user's experiences/views of (health or social care) services

Focus on User (Family carer) – professional relations and perceptions

Impact of equipment aids and technology

Personal tragedy/ experience of terminal/progressive illness

Reference	Buck, D., Jacoby, A., Baker, G. A., Graham-Jones, S., & Chadwick, D. W. 1996, "Patients' experiences of and satisfaction with care for their epilepsy", *Epilepsia*, vol. 37, no. 9, pp. 841-849	**Ref No**	NO.053
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 T2 **T3** T4		
Location of study	**UK** Other		
Long Term Condition	**Epilepsy**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Study (postal questionnaire) carried out by team from University of Newcastle on Tyne/ Dept. of Neurosciences Walton Hospital Liverpool to determine satisfaction with care, studying patient's experience of GP and hospital clinic care for epilepsy and their views about the provision of information concerning management of their condition. Appears to have been based on 677 patient responses. Following points of interest:

Doctor's interpersonal skills were the most influential factors affecting both patient satisfaction overall and the likelihood that doctors might discuss with patients certain clinical and social issues surrounding the management of their condition.

A sizeable proportion of patients report they received insufficient information about epilepsy, both from hospital doctors and GPs.

Patients place great importance on having a doctor who is approachable, communicative and knowledgeable and on receiving adequate information about their condition

Clinicians may need to be made more aware of the importance of accessibility and sensitivity to the non-clinical needs of patients.

Reference	Cochrane, J. 1995, "Patient education-lessons from epilepsy", *Patient Education and Counseling*, vol. 26, no. 1-3, pp. 25-31.	**Ref No**	NO.054
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Epilepsy**		
Confidence Rating	**High** Though experientially based Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Paper presents a strong argument in favour of patient education in epilepsy (on the nature of the condition, management of, coping with).

The perspective is that of someone with epilepsy who works for lay epilepsy associations (Scotland, Ireland) (exact role unclear). Author has considerable experientially based knowledge in the field.

The case it made that health services (secondary and primary care, multidisciplinary teams) must include patient education in their work, because patient education results in:

Patient confidence in challenging discrimination/stigma.
Better seizure control.
Greater compliance with treatments.
Increased health and well-being of patients and their families.
Greater patient self-confidence and self-esteem.
Greater patient control of their condition and life in general.

The author sets out the content (protocol) of a patient education programme, to be available to both patients and families.

Reference	Segar, J. & Abati, F. G. 1994, "Negotiating illness-disability grants and the treatment of epilepsy", *Medical Anthropology Quarterly*, vol. 8, no. 3, pp. 282-298.	**Ref No**	NO.056
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 T2 **T3** T4		
Location of study	UK **Other**		
Long Term Condition	**Epilepsy**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Account of the process of applying for disability grants(DG) for epilepsy in S.Africa. Users' experiences are dominated by extreme poverty and unemployment, leading many people to claim they have epilepsy in order to attract a DG. The process of obtaining a DG is made very difficult but if it can be achieved appears to make a huge difference to the income levels of the families that it enters so they are highly prized. Inevitably, some people try to defraud the system and this means that the health professionals have a devil of a job to sort out who genuinely has epilepsy and who does not.

Management of epilepsy involves regular medication (anti-epileptic drugs to prevent fits). The health professionals believe that if patients take their medication regularly they will avoid fits. The drugs have unpleasant side effects. The system that is in place relies upon 'compliant' patients who are not disorganised and who medicate as instructed. In reality hardly any do, due in part to chaotic lifestyles owing to poverty. Blood tests are regularly administered at the clinics and patients have to bring calendars and any leftover medication with them to appointments. Failure in any of these respects can mean the end of the DG application, or its removal, both of which are clearly disastrous financially.

Very little in this article that actually bears on the UK position but there are some lessons perhaps in the difficulties of providing health care to patients experiencing extreme poverty and the complicating effects of a punitive health care system.

Reference	Bloch, S. 2001, "Communication and MND: A few professional reflections", *Thumb Print*, vol. Autumn 2001.	**Ref No**	NO.057
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Motor Neurone Disease**		
Confidence Rating	High Medium **Low**		

Key points to user’s experiences/views of (health or social care) services

Speech therapist outlines his PhD research project on changes in mechanics of conversation between people with MND and their partners

Interest in family involvement in support/listening highlighted

Reference	Wilson, F. C., Harpur, J., Watson, T., & Morrow, J. I. 2002, "Vegetative state and minimally responsive patients - Regional survey, long-term case outcomes and service recommendations", *Neurorehabilitation*, vol. 17, no. 3, pp. 231-236.	**Ref No**	NO.058
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Brain injury (persistent vegetative state)**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

Study carried out in Northern Ireland, regional survey of consultant level neurology, neurosurgical and rehabilitation staff to identify retrospective estimate of patients in vegetative or minimally responsive states from their own clinical caseloads (October 1995-97) 35 patients were identified, majority were not placed in specialist brain injury facilities following acute hospital interventions, The following findings are of tangential interest (as it might be thought questionable the extent to which patients in PVS can be said to have 'user experience' and so few studies, this article is probably important):

Of 12 patients referred as being vegetative or in minimally responsive state, 4 were considered as having been misdiagnosed (emerged) at follow up, 2 had been presumed to be vegetative for at least one year. All patients remained severely physically disabled (i.e. totally dependent for care) but four were nevertheless able to communicate their preference in quality of life issues, care decisions etc either by verbal or non-verbal means.

These patients need skilled and frequently prolonged assessment, appropriate management from inter-disciplinary as opposed to multi-disciplinary team working style – as skill repertoire equips them to recognise often subtle improvements in cognitive function and act to maximise individual patient's quality of life.

Current paucity of service provision for these vulnerable groups of patients is highlighted. Calls for establishment of a regionally situated dedicated service to this patient group.

Reference	Oliver, D. 2000, "Hospices - a lifeline to normality", *Thumb Print*, vol. Summer 2000, p. 6		**Ref No**	NO.059
Research methods	Quantitative	Qualitative	Mixed	**Other**
Typology	**T1**	T2	T3	T4
Location of study	**UK**		Other	
Long Term Condition	**Motor Neurone Disease**			
Confidence Rating	High	Medium	**Low**	

Key points to user's experiences/views of (health or social care) services

Hospice care philosophy (and its different forms) outlined by Consultant in Palliative Medicine

Social aspects of care highlighted

Reference	Thumb Print 2002, "Physiotherapy", *Thumb Print*, vol. Winter 2002-2003, pp. 6-7.	**Ref No**	NO.060
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other (USA)		
Long Term Condition	**Motor Neurone Disease**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

Article is about physiotherapy and how it can relieve symptoms of MND

- Mobility problems, sitting comfortably, climbing stairs, getting in and out of bed can all become difficult as muscles weaken as disease progresses – physio can be very helpful here
- People with MND want to preserve maximum level of mobility for as long as possible. Exercises can improve muscle function and physio can help people achieve a full a range of movement as possible. Exercises that relieve spasticity, pain and stiffness as well as help prevent muscle cramps and joint deformity can make a considerable difference to quality of life.
- Physio can help improve balance, posture and co-ordination.
- Rest and relaxation are vital for people with MND

Reference	Hogan, B. A. 1999, "Narrative therapy in rehabilitation after brain injury: a case study", *Neurorehabilitation*, vol. 13, no. 1, pp. 21-25.	**Ref No**	NO.061
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Brain injury**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

This is a single case study, largely methodological/theoretical, describing narrative therapy as used with a brain injured patient. As such the user experience is submerged beneath the rhetoric. It appears that narrative therapy can be useful for some individuals with this condition.

Reference	Rosenthal, M. 1996, "1995 Sheldon Berrol, MD senior lectureship: The ethics and efficacy of traumatic brain injury rehabilitation-myths, measurements, and meaning", *Journal of Head Trauma Rehabilitation*, vol. 11, no. 4, pp. 88-95.	**Ref No**	NO.062
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Traumatic brain injury**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

A keynote address looking at the development of brain injury rehabilitation over the last twenty years. Full of methodological insights and politics it nevertheless ignores a user perspective.

Reference	Howard, R. S. & Orrell, R. W. 2002, "Management of Motor Neurone disease", *Posgraduate Medicine Journal*, vol. 78, no. 926, pp. 736-741.	**Ref No**	NO.063

Research methods	Quantitative	Qualitative	Mixed	**Other√**
Typology	T1	**T2**	T3	T4
Location of study	**UK**	Other		
Long Term Condition	**Motor Neurone Disease**			
Confidence Rating	**High**	Medium	Low	

Key points relating to user's experiences/views of (health or social care) services

This article presents detailed guidelines on the clinical management of the patient with MND, including palliative care. It does not report data on the users' experience of the health service, but does draw on the authors' clinical experience concerning patients needs.

Emphasis is placed on the need to handle patients and carers with sensitivity, especially in conveying the diagnosis. It is noted that patients require full information.

Reference	Banja, J. & JOHNSTON, M. V. 1994, "Outcomes Evaluation in TBI Rehabilitation part 3. Ethical Perspectives and Social Policy", *Archives of Physical Medicine and Rehabilitation*, vol. 75, no. 12, p. SC19-SC26.	**Ref No**	NO.065
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	T1 **T2** _ T3 **T4**		
Location of study	UK **Other**		
Long Term Condition	**Traumatic brain injury (tbi)**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

An ethical discussion on values versus outcomes in the treatment of TBI. No user perspective is offered.

The authors note the person-centredness of the rehab approach but contrast this with the functional assessments that prevail in professional intervention. They argue for a new paradigm in treatment of TBI that ensures a place for the individual at the core of the care planning process.

Reference	Carrillo, E. H., Gonzalez, J. K., Chacon, P. M., Kirton, O. C., & Byers, P. M. 1998, "Spinal cord injuries in adolescents after gunshot wounds: an increasing phenomenon in urban North America", *Injury - International Journal of the Care of the Injured*, vol. 29, no. 7, pp. 503-507./	**Ref No**	NO.066
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Spinal cord injury**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

The aim of this study was 'to determine the expense of acute medical care and rehabilitation experience'. This was done almost exclusively in $US.
The authors recognise that there are individuals behind the statistics but do not attempt to elicit their views.

Reference	Stiens, S. A., Bergman, B. S., & Formal, C. S. 1997, "Spinal cord injury rehabilitation. 4. Individual experience, personal adaptation and social perspective", *Archives of Physical Medicine & Rehabilitation* , vol. 78, no. 3, p. s65-s72.	**Ref No**	NO.067

Research methods	Quantitative	Qualitative	**Mixed**	Other
Typology	T1	**T2**	T3	T4
Location of study	UK		**Other (USA)**	
Long Term Condition	**Spinal Cord Injury**			
Confidence Rating	**High**	Medium	Low	

Key points relating to user's experiences/views of (health or social care) services

This is a 'learner-directed module' rather than research but it is a useful review source. It explores:

- Models of the multi-system effects on a person after SCI
- Disablement
- Theories of adjustment
- Patient autonomy
- Quality of life
- Community experience
- Adaptations
- Enhancing sexuality
- Minimization of pain after SCI

Perspectives of the patient's experience in disablement, interdisciplinary, person-centred rehabilitation and success of the individual in chosen life roles are emphasized.

Reference	Baylis, T. 1995, *Motor Neurone Disease: A Patients Perspective* MNDA, London.	**Ref No**	NO.068
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Motor Neurone Disease**		
Confidence Rating	**High (personal account)** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

This is a short paper written by a man with MND, published by the MND Association – 'A Patient's Perspective'. Presented to an audience (probably of the MNDA, but this is not known).

The piece outlines the author's illness experience, daily life and attitudes. A few references are made to his encounters with health services:

The medical specialist did not disclose the diagnosis.

No form of medical treatment exists.

Health professionals require advice and information from people with expertise, such as MNDA Advisers.

Reference	Craig, A. & Hancock, K. 1994, "Difficulties in Implementing Group Cognitive-Behavior Therapy for spinal cord injured persons - a clinical discussion", *Australian Psychologist*, vol. 29, no. 2, pp. 98-102.	**Ref No**	NO.070
Research methods	**Quantitative** Qualitative Mixed Other But small numbers – 20 patients		
Typology	T1 **T2** T3 T4		
Location of study	UK Other Sydney Au.		
Long Term Condition	**Spinal Cord Injury**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services
Patients' views of a group CBT (Cognitive Behaviour Therapy) programme:

Majority were initially reluctant to participate, e.g. saw it as suggesting they needed psychiatric help. Consented when objectives of CBT explained. (a skills-based therapy which focused on coping with real life situations)

Post CBT group programme:
90% agreed or strongly agreed programme had been useful
Majority (over 75% in all cases) agreed or strongly agreed that the programme had meant they had acquired skills to help them:
Control anxiety levels; control depressed mood; live their life as a person with sexual needs; cope with future problems; improve communication and assertion skills.
(and they stuck with these positive views at a six month follow up)

90% of participants recommended the programme should be a standard component of rehabilitation for people with SCI.

Paper has interesting discussion of characteristics of SCI patients in Australia and the ways in which CBT group programmes may be best adapted to suit this group. However not user views.

Reference	Jenkinson, C., Fitzpatrick, R., & Peto, V. 1999, "Health-related quality of life measurement in patients with Parkinson's disease", *Pharmacoeconomics*, vol. 15, no. 2, pp. 157-165.	**Ref No**	NO.073
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Parkinson's Disease**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Majority of this article is on methodological issues relating to comparison of NHP, SIP, SF36, PDQKL and PDQ39 quality of life measurement issues. There are some valid points made in the literature review (although these are not findings from this research, but 'secondary' reporting):

Several epidemiological surveys have demonstrated the important of physical disability in PD particularly walking, moving around in bed and around the house and mobility in public areas.

Falls are a common hazard for people with PD – in one study 13% of patients reported falls which occurred more than once a week. As a result hip fractures are common

PD patients reported more work-related problems than matched healthy individuals

More limitations in relation to household manage

Social isolation and limited leisure; in 1 study 50% of individuals with PD reported restricted social activities. Over two thirds of patients attending a specialist PD clinic reported giving up a hobby because of PD

Difficulty taking holidays

Financial difficulties – 19% of individuals with PD experienced these

Premature retirement from work – reduced income

Significantly more health-related costs than matched healthy individuals

Emotional well being – up to 30% experienced depression

Loss of control over life, loss of confidence and embarrassment and stigma arising from symptoms.

Cognitive impairment – 33% concerned about problems of concentrations

One third experienced difficulties with speech

Reference	Carus, R. 1980, "Motor neurone disease: a demeaning illness", *British Medical Journal*, vol. 280, no. 6212, pp. 455-456.	**Ref No**	NO.074
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Motor Neurone disease**		
Confidence Rating	**High** (personal view) Medium Low		

Key points relating to user's experiences/views of (health or social care) services

This is a 'Personal Paper' in the BMJ, written by a man with motor neurone disease. He writes angrily about the lack of knowledge and understanding of MND displayed by many doctors and by the general public. The message is that medicine has not helped him, has sometimes abandoned him ('nothing I can do'), and has often dealt badly with himself and his wife (e.g. on not giving information about the diagnosis).

Reference is made to the setting up of the MND Association in Nottingham, which has brought to light similar experiences by patients and carers.

Reference	Crischilles, E. A., Rubenstein, L. M., Voelker, M. D., Wallace, R. B., & Rodnitzky, R. L. 1998, "The health burdens of Parkinson's disease", *Movement Disorders*, vol. 13, no. 3, pp. 406-413.*l*	**Ref No**	NO.075
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Parkinson's disease**		
Confidence Rating	High Medium Low		

Key points relating to user's experiences/views of (health or social care) services

A quality of life survey attempting to show associations between stage of disease and health related quality of life. As such any user perspective is NOT related to services but to an assessment of quality of life issues. These were rated on eight scales in an attempt to 'quantify the burden of illness' for Parkinson's disease.

The study cites much relevant literature and highlights new areas for investigation and although it rates high for confidence it is NOT relevant to this project.

Reference	MNDA 2002, *The Motor Neurone Disease Association's Survey of Occupational Therapists* MNDA, London.	**Ref No**	NO.076
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Motor Neurone Disease**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

This paper does not provide information on users' experiences of services.

The paper reports the results of an MND Association survey of Occupational Therapists. The questionnaire was placed in OT News.

The purpose was to identify OTs' experience and knowledge of MND, as well as their knowledge of relevant policies/guidelines/protocols and of the MND Association.

A simple frequency count is given for each question.

Reference	*MNDA 2001,* Tracking Survey 2001 *MNDA, London.*	**Ref No**	NO.077
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Motor Neurone Disease**		
Confidence Rating	High Medium **Low**		

Key points to user's experiences/views of (health or social care) services

Postal survey – basic quantitative approach although described as 'mixed

Examines role of MND Association and lay/ carer knowledge of its services

Focus on equipment aids and advice

Stresses length of time to be diagnosed with MND and ways professionals communicate diagnosis

Reference	MNDA 2002, *Report on the survey of views and experiences of people with Motor Neurone disease* MNDA, London.	**Ref No**	NO.078
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Motor Neurone Disease**		
Confidence Rating	**High** - Study has been replicated 3 times successfully		

Key points relating to user's experiences/views of (health or social care) services

5 most important priorities for people with MND:

- more research into MND
- increasing knowledge about MND among professionals
- increasing knowledge about MND among the public
- more effective lobbying on behalf of people with MND
- better coordination of services

Most people found out about the MND Association through their diagnosing consultant
Information leaflets were generally considered the most useful means of delivering information about MND

Were expressed concerns about diagnosis –

- the delay in being diagnosed
- the manner in which the diagnosis was given
- lack of information at the time to of diagnosis

Slow follow up by neurologist after diagnosis
Concerns about time taken to refer patients to relevant services and professionals (too long!)
Delays in supplying equipment and adaptations – too much red tape.

Reference	van Teijlingen, E. R., Friend, E., & Kamal, A. D. 2001, "Service use and needs of people with motor neurone disease and their carers in Scotland", *Health & Social Care in the Community*, vol. 9, no. 6, pp. 397-403.	**Ref No**	NO.080
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Motor Neurone Disease**		
Confidence Rating	**Medium** - could be replicated but interviewer should not have professional interest in findings (may bias responses)		

Key points relating to user's experiences/views of (health or social care) services

Study on use of, need for, and satisfaction with services among people with MND and their carers.

Methods: Questionnaire used in 153 interviews with people with MND in Scotland. 60% of sample were severely disabled.

Findings of relevance:
Only 28% reported that the health services met their needs completely, with 25% reporting the same for social services. However, only a very small proportion (3-6%) said that these needs were not met at all.
A key problem is that the disease can deteriorate quickly, changing needs, while services are only able to react slowly.
People with an identifiable carer were more likely to have their health [service] needs met than those without.
31% of carers would have liked more help. Disturbed sleep was a key problem.
Since nearly one-quarter of all respondents were not currently followed up in hospital, and two out of five were not currently attending a hospital clinic, the implication is that provision of or planning for care for at least part of this group needs to be organised by community-based services".
There were regional variations within Scotland on use of and satisfaction with services.

Reference	Gottberg, K., Einarsson, U., Fredrikson, S., von Koch, L., & Holmqvist, L. W. 2002, "Multiple sclerosis in Stockholm County. A pilot study of utilization of health-care resources, patient satisfaction with care and impact on family caregivers", *Acta Neurologica Scandinavica*, vol. 106, no. 5, pp. 241-247.	**Ref No**	NO.081
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other (Sweden)**		
Long Term Condition	**Multiple Sclerosis0**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

The research explored the feasibility of calculating utilization of health-care resources within a given area (Stockholm County) and evaluated methods for interviewing people with MS and carers.

Methods

Home visits made to 26 people with MS with different levels of impairment and types of housing. Structured interviews assessed patient satisfaction, use of technical aids and home adaptations, help from municipal and family carers, and health related quality of life.

The study is a pilot for a population-based survey of people with MS in Stockholm county (n = 2000).

Key findings

It was clear that the proposed larger scale survey was feasible due in part to the enthusiastic involvement of people with Ms and their carers.

Additional areas to be included are items relating to information and advice on social security and psycho-social issues, information delivered in the early stages of the disease and relating to the perception of the situation when the diagnosis of MS was given.

The focus of this paper was on the feasibility of the proposed larger study and as such did not discuss service user views.

Reference	Berk, C., Carr, J., Sinden, M., Martzke, J., & Honey, C. R. 2002, "Thalamic deep brain stimulation for the treatment of tremor due to multiple sclerosis: a prospective study of tremor and quality of life", *Journal of Neurosurgery*, vol. 97, no. 4, pp. 815-820.	**Ref No**	NO.082
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

This is a clinical paper reporting the nature and effects of a surgical intervention to reduce tremor in MS patients (12 patients).

It is <u>not</u> a paper about patients' views and experiences of services per se.

It notes, in brief, that the results of a patient satisfaction survey (post-surgery) indicate that patients' were roughly evenly divided on:

whether, given similar circumstances, they would undergo the procedure again

satisfaction with the results of surgery

whether the surgery had made their life better.

It is concluded that the surgery does reduce tremor in some patients, but that this did not always translate into improved quality of life.

Reference	Miller, C. & Jezewski, M. A. 2001, "A phenomenologic assessment of relapsing MS patients' experiences during treatment with interferon beta-1a", *Journal of Neuroscience Nursing*, vol. 33, no. 5, pp. 240-244.	**Ref No**	NO.083
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	High Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Sufferers report relief followed by fear on receiving the diagnosis

Sufferers report uncertainty over the varying drug regimes they are offered

Some sufferers report very positive experiences with representatives of the drug manufacturers through telephone support

Sufferers made use of education on injection technique and coping with side effects from clinic staff and other sufferers

Reference to follow up?
Miller, C. (1997) The lived experience of relapsing multiple sclerosis: a phenomenological study *Journal of Neuroscience Nursing* 29, pp294-304

Reference	Somerset, M., Campbell, R., Sharp, D. J., & Peters, T. J. 2001, *"What do people with MS want and expect from health-care services?",* Health Expectations, vol. 4, no. 1, pp. 29-37.	**Ref No**	NO.084
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	**High** Medium Low		

Key points to user's experiences/views of (health or social care) services

Employs standard quality of life measures (SF-36 and index of depression) to examine user perceptions of illness and use of different therapies/therapists

Focus on medical condition and associated patient needs

Conclusion includes reference to involving users more in their medical treatment

Reference	Dunk, J. & Swales, T. 2000, "Multiple sclerosis: a fast-track service", *Nursing Times*, vol. 96, no. 25, pp. 35-36.	**Ref No**	NO.085
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Multiple sclerosis**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

A very short report in Nursing Times on the general level of dissatisfaction with services for MS sufferers and the proposals for a new fast-track system that targets resources, particularly in relation to administering IV methylprednisolone.

Reference	Howarth, A. L. 2000, "Pain management for multiple sclerosis patients", *Professional Nurse*, vol. 16, no. 1, pp. 824-826.	**Ref No**	NO.087
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Aim: explore the prevalence of pain in patients with MS

Up to 75% of patients with MS experience pain. May be caused by the disease or the disability ensuing from the disease
Common pain syndromes in MS are:
Dysaesthesia – unpleasant sensation described as burning, lancinating or shooting
Trigeminal neuralgia – sharp intense sensation in upper part of face
Musculo-skeletal pain – often in the back or in weight bearing joints

Pain shown to increase in prevalence in relation to the time passed since diagnosis. Patients are more susceptible to experiencing pain the longer they have had the disease.
36% of patients were concerned about mobility as a symptom of MS
35% of 316 patients reported pain as a symptom that they were most concerned about.

This research has been followed by an educational programme implemented for patients newly diagnosed with MS. Pain management awareness is included in this .
A further study is planned to evaluate the efficacy of aromatherapy massage in patients with MS and pain.

Reference	Parkinson's Disease Society 2002, *Parkinson's disease and Hospital Stays* Parkinson's Disease Society, London.	**Ref No**	NO.089
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Parkinson Disease**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Aim: to highlight some of the key aspects of Parkinson's for health professionals to be aware of.

Listening to the patients and their families, and respecting/ valuing their experiences – involve them in the management of their condition. Patients often have strategies to manage their lives
Nature of disease is different for every patient with PD. Symptoms and way of progressing is also variable
Drugs can control symptoms of PD, but needs to be taken at specific times. Also patients may have very different combinations of drugs, because Parkinson's is a very individual condition. Therefore need to assess individual. Further need to continue assessing patients' condition as drug doses need adjusting as condition progresses
Side-effects of drugs – wearing off effect of drugs, and 'on-off syndrome' where the drugs sometimes work and sometimes don't thus can cause fluctuations in motor function
Contraindicated drugs may be used in hospitals to treat complications that may arise, E. G sickness, dizziness or psychosis. Unfortunately , these drugs worsen the symptoms of PD.
PD can affect communication: speech, hearing, body language. Communication difficulties can give out misleading signals to health professionals. Professionals need to look behind the mask, see the person beneath. Need to give patient time to respond.
Patients need to be kept mobilized by physiotherapy
Patients with PD are prone to weight loss, infection and depression. Need nutrition. May be very slow to eat a meal, but the staff need to be patient with them
Need to discuss administration of drugs with Parkinson's disease specialist.
Anaesthetist should know drugs taken by patients before surgery

Reference	Reynolds, H., Wilson-Barnett, J., & Richardson, G. 2000, "Evaluation of the role of the Parkinson's disease nurse specialist", *International Journal of Nursing Studies*, vol. 37, no. 4, pp. 337-349.	**Ref No**	NO.090
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other (USA)		
Long Term Condition	**Parkinson's Disease**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

A one year follow up study of 108 randomised patients with PD at three centres was performed to investigate the differences between care provided by the hospital based PD nurse specialist (PDNS) compared with the consultant neurologist (control)

- Only 2 out of 22 differences were found where physical functioning and general health improved more in the control group
- Provision of PDNS for patients with PD cannot therefore be recommended solely on cost-effectiveness grounds because of similar outcomes but increased costs with PDNS providing additional care.
- However, medical and nursing specialists valued their complementary expertise and patient and carers responses to consultations also reflect that PDNS's have particular contributions.

Reference	Lacroix, A., Jacquemet, S., & Assal, J. P. 1995, "Patients' experiences with their disease: learning from the differences and sharing the common problems", *Patient Education & Counseling*, vol. 26, no. 1-3, pp. 301-312.	**Ref No**	NO.092
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 T2 T3 **T4**		
Location of study	UK Other		
Long Term Condition	**Epilepsy, PD and other 'chronic diseases'**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

The paper presents a series of statements by patients (mainly from Switzerland) and its aim is "that the burden those patients have to carry because of their disease can be seen, and heard, in order to be better recognised"

Epilepsy (Patient from the Epilepsy Association of Scotland)
Psychological costs. Experience of loss felt by many people with Epilepsy (confidence, self-worth, self-esteem, independence). Often feel no longer in control, vulnerable disempowered and disadvantaged.
Professional costs. Ill-founded assumptions about the condition acts as a barrier to training and employment
Costs to family life – diagnosis can be hard to accept for family members, concerns about safety and 'appropriate' behaviour (i.e. alcohol consumption driving) need to be managed.
Financial costs such as travelling to medical appointments, damage to clothes and other items during seizures, higher than average rates of injury, use of specialist aids and often one-to-one care by an informal carer.
One patient described how they wanted a true partnership between patient and doctors which would require better communication and more information.
Changing the focus and control of treatment plan to patient

Parkinson's Disease (Swiss Parkinson's Association)
Psychological costs –additional burden of fluctuating symptoms and public perceptions of symptoms (i.e. appears drunk)
Professional costs – many patients withdraw from social life to avoid attention, the condition can also affect communication. This can end careers, result in loss of position or retirement.
Social costs – heavy strain on relationship with relatives (especially when overlaps with carer).
Financial costs – not all additional costs are met by health insurance or other forms of social support.
Other patients want better information from the start about their condition, better understanding about their medication, importance of paramedical help (physical/occupational therapy).

There is no analysis of the patient statements.

Reference	Darragh, A. R., Sample, P. L., & Krieger, S. R. 2001, ""Tears in my eyes 'cause somebody finally understood": client perceptions of practitioners following brain injury", *American Journal of Occupational Therapy*, vol. 55, no. 2, pp. 191-199.	**Ref No**	NO.095
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	Brain Injury		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

This paper describes itself as a phenomenological qualitative study. Opportunistic sampling and snowball sampling methods were used with initial contact being made to 13 support groups in the state of Colorado, USA. 51 people with acquired brain injury were interviewed. Each participant gave one-open ended in-depth interview.

'Thematic analysis' revealed 3 main themes related to the perceived qualities and practices of service providers: the *roles of provider*, the *helpfulness of the services provided* and the *personal characteristics of the provider*.

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The roles of provider

Respondents emphasised the interpersonal relationship between themselves and the service provider rather than the provider's technical expertise. For example patients referred to their therapists as *friend* or *mentor*.

Participants emphasised the wish to be included as part of a team so that they felt in control of their treatment.

Good service providers were also advocates for the needs of their clients, providing information, case management, and assistance with referrals. When providers do not plat these roles their services became frustrating.

The helpfulness of the services provided

Occupational therapists were frequently mentioned in relation to the relevant, meaningful, and practical suggestions and strategies they suggested. Some participants mentioned how some practitioners assisted with the development and the use of tools and the learning of new skills to 'compensate' for loss of function.

Participants did not like unhelpful service providers, nor those who provided services that did not feel individualised.

The personal characteristics of the provider

Clear, honest, and straightforward communication was required from the service providers.

Participants valued professionals who would discuss treatment options and solicit patient opinions.

Participants also valued professionals who understood the specific needs of people with brain injury.

Participants were not satisfied with providers who they perceived as unwilling to listen, poor communicators, overly optimistic, overly pessimistic, or tending to minimise the patients symptoms.

Generally 'when the patients reflected on the practitioners who had worked with them, they constantly referred to the many roles the providers played in their lives: a friend, a mentor, a team member, an advocate etc.

Reference	Sample, P. L. & Darragh, A. R. 1998, "Perceptions of care access: the experience of rural and urban women following brain injury", *Brain Injury*, vol. 12, no. 10, pp. 855-874..	**Ref No**	NO.096
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK Other (Colorado US)		
Long Term Condition	**Brain injury**		
Confidence Rating	High **Medium** Low Opportunistic sample of 21 women recruited from support groups run by local Brain Injury Association. The authors describe themselves as having "a consumer-driven, choice focused, non-medical model of service delivery"		

Key points relating to user's experiences/views of (health or social care) services

I've indicated in italics what I think are probably the main generalisable themes for the UK.

Themes:

1. Issues surrounding diagnosis (applied to the half of those interviewed who did not get immediate diagnosis)
2. Barriers to accessing care

1. Diagnosis
Example: delay in diagnosis of silicon poisoning from post-mastectomy breast implant rupture, post concussive syndrome, brain tumour.
sub themes:

Difficulty in obtaining a diagnosis, not being believed when they reported symptoms, or symptoms not being recognised by professionals. *Summed up as physicians and clinicians often not trained to recognise mild brain injury.*

Marginalisation – professionals, and friends and family tending to dismiss problems as not important because less visible and less obviously severe. No diagnosis or misdiagnosis could lead to loss of self esteem and depression, as well as impact on relationships.

Validation – being pleased to get a diagnosis

2. Barriers to access (*people with brain injury may not be in a fit mental state (emotionally and/or cognitively) to negotiate barriers to access, so may need*

assistance to do this. Value of advocacy to some users.)

Financial problems – mostly not relevant to UK context as its about getting insurers to pay out for medical costs, and the costs of accessing support groups and the like.

Having to travel long distances to access rehabilitation services

Lack of services, (particularly in rural areas), inaccurate information about what was available, not being able to get a specialist referral

Reference	Peters, A. V. 1994, "Traumatic brain injury information database: a user survey", *Bulletin of the Medical Library Association*, vol. 82, no. 2, pp. 153-159.	**Ref No**	NO.097
Research methods	Quantitative Qualitative **mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Brain injury**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Users find information about their condition helps them to cope with medical procedures and to manage their health generally.

Users have difficulty accepting information from hospital staff at times of crisis

Users families benefit from information as much as users themselves

Users find that new information on their condition cam lead to networking opportunities and that these are mutually beneficial

(Some networking opportunities led to contacts with groups outside the specific condition)

Users report that they have changed their behaviour based on information received

Reference	O'Day, B., Palsbo, S. E., Dhont, K., & Scheer, J. 2002, "Health plan selection criteria by people with impaired mobility.[comment]", *Medical Care*, vol. 40, no. 9, pp. 732-742.*l*	**Ref No**	NO.098
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**General (cerebral palsy, spinal cord injury, rheumatoid arthritis& MS related to mobility impairment)**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

People with CP are generally worried about the ageing process and communication difficulties they experience with health care professionals

Some MS sufferers find that doctors are not well informed of the condition

Users are generally dissatisfied with health care professionals appreciation of problems associated with everyday living skills

Users sometimes find an assumption on the part of HCPs that cognitive impairment accompanies a physical disability

Many users complained of physical access problems when visiting doctors

Users generally found health insurance a big problem

Possible useful reference:

McLaughlin, C.G. (1999) Health care Consumers: Choices and Constraints *Med. Care. Res. Rev.* (56) suppl. 1,: 24-29 (discussion 60-66)

Reference	Willen, C. & Scherman, M. H. 2002, "Group training in a pool causes ripples on the water: experiences by persons with late effects of polio", *Journal of Rehabilitation Medicine*, vol. 34, no. 4, pp. 191-197.	**Ref No**	NO.99
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other** Sweden		
Long Term Condition	**Polio**		
Confidence Rating	High **Medium** Low 15 individuals 6M 9F. Average age 55. I am confident it reports the views of these users about this intervention.		

Key points relating to user's experiences/views of (health or social care) services
Concerned with late effects of polio (muscle weakness, fatigue, muscle and joint pain). These matter because polio survivors were always strongly encouraged after the acute phase to exercise and undertake lots of physical activity. Now they (professionals) are not so sure this is a good idea in dealing with late symptoms.

This paper describes a physio-led group programme of dynamic exercises in heated water and gives patient responses (N-15) to this (via qualitative interviews). There were measurable physical effects: not reported here as they are not patient views.

Interview date was analysed according to the 'phenomenographic' approach i.e. a qualitative variation exists in how people experience phenomena, and 14 categories were discovered around three aspects of the training programme.

Perhaps sum up user views by saying they found this therapy beneficial in terms of its effect on felt physical symptoms, the pleasure of the process itself and the opportunities for group interaction with others with the same condition.

Participants reported:
The bodily effects
All said felt improved physical capacity, some (just over half) reduced pain
They learnt more about their bodies and their strengths and limitations
The sessions induced feelings of relaxation and well-being

Other effects (reported by 8/15 participants)
Makes everyday life easier, helps with planning life in relation to what is physically possible, and what kind of actions support continued activity. Improved physical function.
Makes you more open to discussing polio with others as well as the group – improves confidence/self-esteem in doing this

The training itself

The water helped people feel free to work as hard as they wished, and be in control of intensity of own movements

The competence of the group leader and her expertise in PPS symptoms is valued – and made them feel safe from demands which might damage them (8/15).

The importance of the group

The group itself was a forum in which friendship and social relationships developed (13/15)

Being in a group with others in the same situation is valued

People exchanged experiences and learned from each other

Reference	Williams, R., Barrett, K., & Muth, Z. 1996, "Service Users' and Carers' Views," in *Mental Health Services. An NHS Health Advisory Service Thematic Review*, R. Williams, K. Barrett, & Z. Muth, eds..	**Ref No**	NO.100
Research methods (in relation to user views)	Quantitative **Qualitative** Mixed Other Six fieldwork visits to units/services by a review group set up by NHS HAS, plus consultation with Headway		
Typology	T1 **T2** T3 **T4**		
Location of study	**UK** Other		
Long Term Condition	Acquired brain injury		
Confidence Rating	High **Medium** Low Its an NHS HAS thematic Review so there is a literature review as well as direct consultations with users and carers. However it was not possible to separate the views of users and carers in the report of views, and the final product was very much the work of professionals, as you might expect.		

Key points relating to user's experiences/views of (health or social care) services

For patients and their families the most important prevailing concern is quality of their life at home and in the wider community.

Experience of medium and longer term progressive increases in social isolation for the person and family members providing care.

Help needed in coping with major changes in roles within the family, and behaviour and personality changes in the person who has experienced brain injury.

Specific opinions about services:
Inexpert assessment of needs, misunderstanding of acquired brain injury, inaccurate diagnosis of behaviour problems

Lack of appropriate facilities for users and carers after the initial acute treatment phase

Access to rehabilitation limited

Respite and long-term accommodation rare, and facilities currently on offer inappropriate for this group

Poor communication between services, hard to find out what is available, GPs do not have enough information about services

Specifically identified needs for: early counselling; information; recognition of needs, and knowledge, of carers.

There were service recommendations (below) tho' they represent a professional response to user views I think, its not totally clear:

Immediately after injury:
Full and accurate assessment of needs of person and any carers.
Provision of information, support and counselling for person, carers and family members soon after.
Post-acute rehabilitation services
Multi-disciplinary teams with knowledge of head injury to link management of acute stage with longer term needs
Community-based services
For those who live with their families: comprehensive range of support services in the community
Also a range of residential service options for people with brain injury.

Aim of therapeutic facilities should be to encourage independence and avoid institutionalisation. Users and carers should be involved in the design and planning of services.

Huntington's disease (does this count?)
Criticisms of the diagnostic process. Difficulties of access to consultants with the right specialist knowledge.

Positive reports of genetic services (?)

Existing centres of expertise valued

Problems of transport to widely distributed specialist centres.

Need for specialist equipment particularly chairs and seating – extreme difficulty in finding this.

Continuity of care valued : e.g. residential services at the same place which provides day services as the condition progresses.

Lack of short term and long term residential services.

Service users value opportunities for meaningful and fulfilling activities

Importance of safety and security

Huntington's Disease Association much valued.

Early onset dementia
Alzheimer's Disease Society has drawn up a declaration of rights for younger people with dementia and their carers.

Problems of diagnosis. GPs not expert in recognising. Person may deny problems.
All the views are carer views – not surprising.

Not clear to me if this group are of relevance. If they are let me know and I will add them.

Reference	Mills, N., Campbell, R., & Bachmann, M. O. 2002, "What do patients want and get from a primary care epilepsy specialist nurse service?", *Seizure*, vol. 11, no. 3, pp. 176-183.	**Ref No**	NO.101
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Epilepsy**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services
An interview study (N=12) (part of a larger study), to examine patient use of a primary care specialist nurse service, focussing on patient expectations and experiences.

Users agreed to see the nurse if they had current problems with the control of seizures and a desire for further information on epilepsy.
Users opted to see the nurse if they were unsatisfied with current care, e.g. poor communication with doctors due to lack of time.
The majority of patients who used the service praised it, even after only one consultation. It was valued for the provision of information, the giving of time to listen to patients' concerns, continuity of care, and empathy.
The community location of the service made it accessible.
Some patients did not see themselves as eligible for the nurse service.
A minority of users noted, one with disappointment, that the nurse could not improve their seizure control (could not prescribe drugs etc).
Key impact of service: enhanced communication between patient and clinician and the provision of information. This was seen as important by patients.
"The study illustrated that effective communication is as much, if not more, of a priority for patients with epilepsy than is controlling the clinical manifestations of their illness" (p.182)

Reference	Couldridge, L., Kendall, S., & March, A. 2001, "A systematic overview--a decade of research. The information and counselling needs of people with epilepsy.", *Seizure*, vol. 10, no. 8, pp. 605-614.	**Ref No**	NO.102	
Research methods	Quantitative	Qualitative	Mixed	**Other**
Typology	T1	**T2**	T3	T4
Location of study	**UK**	Other		
Long Term Condition	**Epilepsy**			
Confidence Rating	High	**Medium**	Low	

Key points relating to user's experiences/views of (health or social care) services

This paper is a review of literature from the last decade relating to epilepsy and as such any user views quoted need to be treated with caution as they do not form the focus of the inquiry and are mediated through professional concerns.

- Users need more *hard* information on their condition (eg medication, diagnosis, written leaflets, lifestyle choices)
- Users benefit from counselling, particularly at the time of diagnosis
- Users value the input from specialist nurses/clinics

Reference	Poole, K., Moran, N., Bell, G., Solomon, J., Kendall, S., McCarthy, M., McCormick, D., Nashef, L., Johnson, A., Sander, J., & Shorvon, S. 2000, "Patients' perspectives on services for epilepsy: a survey of patient satisfaction, preferences and information provision in 2394 people with epilepsy", *Seizure*, vol. 9, no. 8, pp. 551-558.	**Ref No**	NO.103
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Epilepsy**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Aim: provide a comprehensive survey of satisfaction with care, care preferences, and information provision for patients with epilepsy. Use findings to formulate recommendations for development of epilepsy services

Conclusions:

Patient satisfaction and medical preferences

Generally, high level of patient satisfaction with most aspects of care at primary and hospital level

Patients with severe epilepsy were less satisfied with primary care than patients with mild epilepsy – Perception that 'hospital doctors know more about epilepsy'

Patients under 17 years were less satisfied with primary care than hospital care – suggestions that hospital based care is more satisfactory for children and adolescents

Older patients prefer primary care because they are more familiar with the doctor

Information Provision

Deficit in information provision for people with epilepsy. A noted restriction in consultation time limits information provision. Possible solution: make more use of other medical professionals e.g. specialist epilepsy nurses, could provide ongoing information about epilepsy and deal with specific issues as they arise

Care Provision

Ineffective shared care between primary and hospital services. May be due to GPs perceived limited knowledge of epilepsy.

Recommendations:

Hospital care for epilepsy should be reorganized into epilepsy centres which would improve primary-secondary care interface, provide information anytime to patients with epilepsy, and be a place of contact for patients with epilepsy.

Specialist epilepsy nurses would have a primary role in maintaining the centres' objectives

Reference	Ridsdale, L. 2000, "The effect of specially trained epilepsy nurses in primary care: a review.", *Seizure*, vol. 9, no. 1, pp. 43-46.	**Ref No**	NO.104

Research methods	Quantitative **Qualitative** Mixed Other
Typology	T1 **T2** T3 T4
Location of study	**UK** Other
Long Term Condition	**Epilepsy**
Confidence Rating	High Medium **Low**

Key points relating to user's experiences/views of (health or social care) services

This paper is a literature review of specialist nurse interventions in epilepsy and as such contains no direct user views or experiences.

Reference	Mills, N., Bachmann, M. O., Campbell, R., Hine, I., & McGowan, M. 1999, "Effect of a primary care based epilepsy specialist nurse service on quality of care from the patients' perspective: results at two-years follow-up", *Seizure*, vol. 8, no. 5, pp. 291-296.	**Ref No**	NO.105
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Epilepsy**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services.

Patient experience and view presented, indirectly via a limited range of questionnaire items, on use of a specific service levels of satisfaction.

The study aimed to assess the effect of primary-care-based epilepsy specialist nurses on patients' reported health status, perceived quality of life, health care use, attitudes to health care, and provision of information.

Findings suggest that provision of an epilepsy specialist nurse for 1 year improved communication between patients and health professionals and levels of patient satisfaction, but did not affected health status and use of other health services.

Method: quasi-experimental controlled before-and-after design, using questionnaires.

It is reported that patients who saw an epilepsy specialist nurse, in comparison with those who did not were:

less likely to want all or most of their follow-up care to be provided by the GP
but more likely to report their GP care as excellent

less likely to have reported never missing antiepileptic drugs.

Reference	Wallace, H. K. & Solomon, J. K. 1999, "Quality of epilepsy treatment and services: the views of women with epilepsy", *Seizure*, vol. 8, no. 2, pp. 81-87.	**Ref No**	NO.106
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Epilepsy**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services
Aim: experiences of women with epilepsy (treatment and services)
Criticism of services concerned 4 domains of care:
Organisation of services
continuity of care was important to build trust and confidence in the doctor. Patients may receive inadequate care due to lack of clarity of GP's responsibilities.
Poor communication between GPs and specialists
Not enough time for patients consultations

Information provision
Obtaining information about epilepsy and drugs was difficult
Barriers for patients to seek out information
Information about contraception (doctors lack knowledge about effects of anti-epilepsy drugs)

Information about antiepileptic drugs in pregnancy
not given enough information from doctors
conflicting advice

Clinical competence and skills
Patients are lay experts in their condition
Concerns about the shortage of epilepsy specialists
Nurses and patients described experiences of delayed diagnoses and misdiagnoses
GPs lack knowledge of different types of seizures and appropriate drug treatment for them
General impression that GPS not interested in epilepsy – need improved training
Lack of awareness of epilepsy and its treatment among clinical hospital staff
Complaints about doctors' lack of awareness of side-effects of the drugs

Reference	Ridsdale, L., Morgan, M., & O'Connor, C. 1999, "Promoting self-care in epilepsy: the views of patients on the advice they had received from specialists, family doctors and an epilepsy nurse", *Patient Education & Counseling*, vol. 37, no. 1, pp. 43-47.	**Ref No**	NO.107
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Epilepsy**		
Confidence Rating	High Medium Low		

Key points relating to user's experiences/views of (health or social care) services
User views/experiences on satisfaction with health services elicited by semi-structured interview (n44). Transcripts analysed using content analysis to identify major themes.

Findings:
About half of the patients stated that the medical specialist was useful with regards to the explanation of diagnosis they received. Poor explanations were often linked to the specialist's lack of time. GPs were also sometimes seen as too busy, and as not sufficiently expert in epilepsy. More input from a specialist nurse would have been valued at this time.
Many patients commented that the specialist doctor gave insufficient information on side effects.
Most patients reported that neither the specialist nor the GP had explained the social aspects of epilepsy, though some saw this as appropriate.
The specialist nurse was reported as particularly useful in explaining the social aspects of epilepsy. E.g. driving laws.
The nurse was also found to be useful in relieving fears.
The nurse was seen to have time to spend with patients - valued.
Patients often wished they had seen the nurse earlier in their disease career.

Suggestions for nurse-run clinics, similar to those operating in other conditions, such as diabetes, highly approved by respondents.

Reference	Chappell, B. & Smithson, W. H. 1998, "Patient views on primary care services for epilepsy and areas where additional professional knowledge would be welcome", *Seizure*, vol. 7, no. 6, pp. 447-457.	**Ref No**	NO.108
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Epilepsy**		
Confidence Rating	High Medium Low		

Key points relating to user's experiences/views of (health or social care) services

- Users generally want

1. More information on medication
2. More time for talk/discussion of their condition and treatment
3. Information on patient organisations
4. Advice on employment
5. Advice on psychological aspects of the condition

Potential references to follow up…..

Mills, N., Bachmann, M., Harvey, I. *Et al* (1997) Patients' Experience of Epilepsy and Health Care, *Family Practice* **14,** 117-123
Chappell, B. (1992) Patient views on their condition and treatment *Seizure,* **1,** 103-109

Reference	Chaplin, J. E., Wester, A., & Tomson, T. 1998, "The perceived rehabilitation needs of a hospital-based outpatient sample of people with epilepsy", *Seizure*, vol. 7, no. 4, pp. 329-335.	**Ref No**	NO.109
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Epilepsy**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Postal survey carried out to identify the perceived epilepsy rehabilitation needs of a hospital based outpatient population. Response rate 70% in 245 patients being surveyed. Data showed 65% of the total sample wanted more rehabilitation assistance and that 27% required substantial contact with the rehabilitation services.

Most common request was for more medical information both via written material and telephone contact with a specially trained epilepsy nurse.
Approximately one is six patients would like to attend a course on how to live with epilepsy.
Access to a psychologist was most often requested during first year following diagnosis and demand for courses on how to live with epilepsy was highest in the second to fourth years following diagnosis.
Requests for social work assistance were associated with employment issues.
Frequency of seizures, duration of epilepsy and age were significant variables in relation to demand for rehabilitation resources.
General conclusions: minimum standards of rehabilitation service should include greater access to medical information via a variety of authoritative sources, and team based resources are wanted by a substantial proportion of the population in relation to specific and definable problems, which would involve intensive input from psychologists and social workers

Reference	Goldstein, L. H., Minchin, L., Stubbs, P., & Fenwick, P. B. 1997, "Are what people know about their epilepsy and what they want from an epilepsy service related?", *Seizure*, vol. 6, no. 6, pp. 435-442.	**Ref No**	NO.110
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	Epilepsy		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Study sets out to investigate the level of knowledge about epilepsy in general and in relation to patient's own condition (patients attending tertiary referral epilepsy outpatient clinic). Also sought to investigate patient satisfaction with the service and whether knowledge acquired about epilepsy related to that satisfaction
70 out of 94 patients responded to Epilepsy Knowledge Profile Questionnaire (general and personal knowledge of epilepsy) and a questionnaire assessing service satisfaction.

Patients found to know more about epilepsy in general than about their own condition.

Some patients were unable to give accurate indications of their drug regimes.

Over 91% satisfied with the service they received butt this bore no relation to information they had acquired or wanted about epilepsy.

Multidisciplinary services were requested by sizeable percentage of patients but especially access to a specialist nurse in epilepsy.

Study highlights the need for clinicians to check patients' knowledge about their condition and for further work to clarify the source of patients' satisfaction with service delivery.

Reference	Goldstein, L. H., Pender, N., Parshall, A. M., & Fenwick, P. B. 1997, "Patients' and referring doctors' perceptions of treatment on an in-patient neuropsychiatry/epilepsy unit: a study of three cohorts", *Seizure*, vol. 6, no. 1, pp. 13-20.	**Ref No**	NO.111
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Epilepsy**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services
Users report general satisfaction with services
Of those admitted for care/treatment there was a high level of satisfaction with treatment received
A tendency noted for longer admission times to correlate to higher levels of satisfaction with care/treatment
User satisfaction with treatment showed a high correlation with physician's estimates of efficacy of care/treatment

References to follow up…..
Betts, T. (1992) 'Epilepsy services: what people need, what they want, what they get' *Acta Neurologica Scandinavica* **suppl. 140** 95-100

Reference	Scambler, A., Scambler, G., Ridsdale, L., & Robins, D. 1996, "Towards an evaluation of the effectiveness of an epilepsy nurse in primary care", *Seizure*, vol. 5, no. 4, pp. 255-258.	**Ref No**	NO.112

Research methods	Quantitative	Qualitative	**Mixed**	Other
Typology	T1	**T2**	T3	T4
Location of study	**UK**	Other		
Long Term Condition	**Epilepsy**			
Confidence Rating	High	**Medium**	Low	

Key points relating to user's experiences/views of (health or social care) services

A report on the effectiveness of specialist nurses in primary care. Findings are provisional. The data were generated at interview and are presented in tables and discussion. The costs in terms of finances and quality of life are highlighted.
Points to note are……

90% of respondents want more information on their condition
75% specifically wanted info on the side effects of medication
60% wanted to discuss their condition with someone other than a consultant

while epilepsy specialist nurses rate highly in terms of patient satisfaction the authors see their contribution as complementary.

Reference	Upton, D., Thompson, P. J., & Duncan, J. S. 1996, "Patient satisfaction with specialized epilepsy assessment and treatment", *Seizure*, vol. 5, no. 3, pp. 195-198.l	**Ref No**	NO.113
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Epilepsy**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

Aim: patient satisfaction with specialized epilepsy treatment and assessment

High level of satisfaction with services provided by epilepsy Assessment Unit
Patients and their relatives rated the medical services, social work and psychological services very highly – 90% satisfaction among sample
Perceived high improvement in seizure control, drug side-effects and knowledge about epilepsy
Perceived most important service provided by the unit: drug changes
Perceived least important service: learning to became independent
Majority of relatives perceived that the patient had improved following treatment at the specialised unit
Most commonly cited improvements, by relatives, equalled seizure control
Relatives felt that the most important services offered = observations of seizures and drug changes. Least important were educational groups
Majority of patients, attending the centre, felt that their situation had improved after six months.
A multi-disciplinary approach to epilepsy service provision has been highlighted as important

Reference	Parkinson's Disease Society 2002, *Secondary Care and Medication: Involving the User* Parkinson's Disease Society, London.	**Ref No**	NO.114
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Parkinson's Disease**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

Survey results on the standards of care that patients with Parkinson's disease received in hospitals. Admission for either Parkinson's related treatment or for other treatments.

Details re. methods are not given. Structured interviews are suggested. 256 people interviewed in survey.

Key findings:

- Only 52% received their medication for Parkinson's at the correct time (timing critical for symptom control).
- Only 27% of staff understood the 'on/off syndrome' nature of Parkinson's. This was partly related to some patients being admitted for conditions other than Parkinson's (staff may not know of their Parkinson's initially), and partly because 2/3rds of patients knew they would not be able to access a Parkinson's Disease Nurse Specialist while in hospital.
- Needs were often not met: communication needs, mobility needs, special dietary requirements.

Recommendation: patients should be given a more active role in the management of their condition while in hospital, e.g. self-managed medication

<table>
<tr><td>Reference</td><td>Ridsdale, L., Robins, D., Fitzgerald, A., Jeffery, S., & McGee, L. 1996, "Epilepsy monitoring and advice recorded: general practitioners' views, current practice and patients' preferences", <i>British Journal of General Practice</i>, vol. 46, no. 402, pp. 11-14.</td><td>Ref No</td><td>NO.115</td></tr>
<tr><td>Research methods</td><td colspan="3">Quantitative Qualitative Mixed Other</td></tr>
<tr><td>Typology</td><td colspan="3">T1 T2 T3 T4</td></tr>
<tr><td>Location of study</td><td colspan="3">UK Other</td></tr>
<tr><td>Long Term Condition</td><td colspan="3">Epilepsy</td></tr>
<tr><td>Confidence Rating</td><td colspan="3">High Medium Low</td></tr>
</table>

Key points relating to users' experiences/views of (health or social care) services

The patient data was generated by questionnaire as part of a comparative study; the other data sources being the patients’ GPs (also sent questionnaires) and clinical information extracted from their medical records.

Six practices in the South Thames region were chosen for the study. Practices were chosen on the basis that they had kept computerised records for some time. Therefore 'extrapolating results from these practices alone should therefore be done with caution'. 326 patients from these practices had active epilepsy and were aged over 15 years. 255 were sent questionnaires about the service provided for epilepsy care. Patients with 'psychological illnesses' or other severe illnesses were excluded. Key findings were:

40 of 241 patients (17%) reported that they had a regular arrangement to see their GP.

201 patients (83%) reported that they only sought out their GP when they had a particular problem with their epilepsy.

82 of 237 patients (35%) responded that doctors had not provided enough information.

7% of patients belonged to a self-help group.

Patients generally preferred to receive their epilepsy care in a general practice.

Monitoring and advice provision were less than optimal.

Reference	Averis, A. K. 1996, "Patients' opinions: having a say in epilepsy service provision down under", *Seizure*, vol. 5, no. 1, pp. 57-61.	**Ref No**	NO.117
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Epilepsy**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) service

- Clinic users rated the three most important overall factors in the management of epilepsy…

1 availability of a doctor when needed
2 confirmation of diagnosis
3 prescription of medication

- clinic users then rated satisfaction with services…

1. approachability of nursing staff
2. being able to have tests done there and then
3. prescription of anticonvulsant medication

Reference	DiIorio, C. & Manteuffel, B. 1995, "Preferences concerning epilepsy education: opinions of nurses, physicians, and persons with epilepsy", *Journal of Neuroscience Nursing*, vol. 27, no. 1, pp. 29-34..	**Ref No**	NO.118
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **<u>T2</u>** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Epilepsy**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

Users preferred a doctor, rather than a nurse, to have an educating role in all categories of information regarding epilepsy

[all other views ascertained in this study relate to those held by either doctors or nurses]

Reference	Guldvog, B. 1994, "Patient satisfaction and epilepsy surgery", *Epilepsia*, vol. 35, no. 3, pp. 579-584	**Ref No**	NO.119
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK Other (Norway)		
Long Term Condition	**Epilepsy**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

This was a retrospective self-controlled study involving patients who had undergone epilepsy related surgery since 1949. Of the 188 known patients 143 were sent a postal questionnaire. There was an 81% response rate.

The study was concerned with patient satisfaction with the surgical treatment of epilepsy. The user views contained in the paper relate to their satisfaction with the effects of the treatment.

Reference	Jain, P., Patterson, V. H., & Morrow, J. I. 1993, "What people with epilepsy want from a hospital clinic", *Seizure*, vol. 2, no. 1, pp. 75-78..	**Ref No**	NO.120

Research methods	Quantitative	Qualitative	**Mixed**	Other
Typology	T1	**T2**	T3	T4
Location of study	**UK**	Other		
Long Term Condition	**Epilepsy**			
Confidence Rating	**High**	Medium	Low	

Key points relating to user's experiences/views of (health or social care) services

Users feel they don't get enough counselling at the time of diagnosis (although research suggests that this may be to do with retention of information)

Users identified a lack of basic information (e.g. what is epilepsy? what causes it?) as well as a lack of information on more extensive issues (such as social security benefits, employment options and leisure activities) .

Users identify a lack of information on the side effects of medication generally

users identify a specialist nurse clinic as their preferred option for treatment.

Reference	Buzio, A., Morgan, J., & Blount, D. 2002, "The experiences of adults with cerebral palsy during periods of hospitalisation", *Australian Journal of Advanced Nursing*, vol. 19, no. 4, pp. 8-14.	**Ref No**	NO.121	
Research methods	Quantitative	Qualitative	**Mixed**	Other
Typology	T1	T2	**T3**	T4
Location of study	UK	**Other**		
Long Term Condition	**Cerebral Palsy**			
Confidence Rating	**High**	Medium	Low	

Key points relating to user's experiences/views of (health or social care) services

Study conducted in Australia, The Spastic Centre, NSW on the experiences of 31 self-selected adults with CP during periods of hospitalisation (questionnaire study) Aim was to find out how people with CP are treated by nursing staff. Key findings include:

Many patients felt hospital staff have limited knowledge and skills in caring for people with CP

This results in basic care needs not being adequately addressed during periods of hospitalisation

Changes in nursing assessment, continuing education and discharge planning are recommended

Many respondents reported multiple admissions to hospital within the previous 2 years

Only 23% of respondents reported being asked by hospital staff for information about their disability-specific needs as part of the admission process

The majority of respondents (>60% in all disability categories except medication) felt these needs were never, almost never or only sometimes met by hospital staff

Staff mostly perceived as ignorant of how to care for people with CP.

Reference	Darrah, J., Magil-Evans, J., & Adkins, R. 2002, "How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery", *Disability & Rehabilitation*, vol. 24, no. 10, pp. 542-549.	**Ref No**	NO.122
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Cerebral palsy**		
Confidence Rating	**Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

Satisfaction with services over six areas was rated by families AND their members with CP using a seven-point Likert type scale. further semi-structured interviews with users highlighted the following…

Certain individuals within the services had positively influenced their feelings by investing time and interest
Family members complained of having to 'work the system'
Adolescent users complained of professionals talking over their heads and using jargon
adolescent users wanted to have more input on decision-making and that this was always deferred to parents
adolescents complained of bullying by peers in educational settings

Reference	Engel, J. M., Kartin, D., & Jensen, M. P. 2002, "Pain treatment in persons with cerebral palsy: frequency and helpfulness", *American Journal of Physical Medicine & Rehabilitation*, vol. 81, no. 4, pp. 291-296.	**Ref No**	NO.123
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Cerebral Palsy**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Article is about treatment of pain for people with CP. Authors tried to identify interventions currently being used for adults with CP and to examine the perceived helpfulness of them, determine the extent to which these individuals were accessing services of healthcare providers for the explicit purpose of addressing pain. It is a retrospective descriptive study of 64 adults with cerebral palsy-related chronic pain. Patients were 18-76 years, 35 women and 29 men – using a protocol-based interview.

Results:

- The patients sought and used a variety of pain treatments and healthcare providers and rated many of the interventions as being at least moderately helpful.
- Despite the reported helpfulness of the pain interventions, however, most are only being used by a small subset of the sample
- The majority of the sample with chronic pain did not access health care providers for help in managing their pain. Cerebral palsy related pain is undertreated in the adult population with CP.

Reference	Kilgore, K. L., Scherer, M., Bobblitt, R., Dettloff, J., Dombrowski, D. M., Godbold, N., Jatich, J. W., Morris, R., Penko, J. S., Schremp, E. S., & Cash, L. A. 2001, "Neuroprosthesis consumers' forum: consumer priorities for research directions", *Journal of Rehabilitation Research & Development*, vol. 38, no. 6, pp. 655-660.	**Ref No**	NO.124

Research methods	Quantitative	**Qualitative**	Mixed	Other
Typology	**T1**	T2	T3	T4
Location of study	UK	**Other**		
Long Term Condition	**Spinal cord injury**			
Confidence Rating	High	**Medium**	Low	

Key points relating to user's experiences/views of (health or social care) services

Report of a 'consumer priorities for research directions in neuroprosthesis field in the United States (Cleveland); only 9 participants with SCI took part, exploring the field of functional electrical stimulation (FES) (some had direct experience, some did not) and impact of technologies on their lives. Interesting findings emerged:

Ultimate goal; to be able to walk again, kick ball with children, dance with spouse

Issue of time; frustration at amount of time it takes to perform activities of daily living – negative impact on lives (eg, time-consuming bowel/bladder routines)

Longing to be able to socialise

FES users expressed desire for further miniaturisation and making components internal and waterproof with finer degrees of control

Risks and benefits of increasing dependency on FES – some would be unwilling to endure frequent hospitalisation – others would endure whatever it takes

Some unwilling to have foreign materials implanted as SCI is not life-threatening

Reversibility is an important consideration of any FES since in future technologies may be superior

Limitations of FES still very apparent at present time

Reference	Murphy, D. & Reid, D. B. 2001, "Pain treatment satisfaction in spinal cord injury", *Spinal Cord*, vol. 39, no. 1, pp. 44-46.	**Ref No**	NO.125
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 T2 **T3** T4		
Location of study	UK **Other**		
Long Term Condition	**Spinal cord Injury**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Study conducted in the USA; survey of pain treatment satisfaction; individuals chosen randomly with respect to age and gender from the SCI registry of the Commonwealth of Virginia. SCI complete or incomplete and injured at least 1 year. Mean age 42 years, 69% male and 16% female. Interesting findings include:

72% had cervical injuries and one a mixed cervical/thoracic level injury. 15 patients did not indicate level of injury. 70% reported shoulder pain while 74% reported dysesthetic pain.

Of those with shoulder pain, 70% indicated they had pain for 6 months or longer

The majority of subjects reporting pain received some form of treatment – frequently ibuprofen, hot pack and narcotics.

In general treatment for shoulder pain was perceived as more effective than treatment for dysesthetic pain. Few in chronic pain program

67% of those with shoulder pain and 65& of those reporting dysesthetic pain reported specific adverse effects on lives with most frequent being recreation, self-care and social.

40% of those with shoulder pain rated their worst pain as 7 or higher on a scale of 1-10 (1= no pain 10 worse possible pain). On same scale 57% of those with dysesthetic pain rated their worst pain as 7 or higher.

Only 19% were satisfied with medical treatments received. 49% were dissatisfied and 32% did not respond to this question.

Some of the respondents indicated the treatment either did not work or did not work long enough for them to consider any of the options tried with them as successful. Authors believe not all pain management avenues were adequately tried with this group.

Reference	Lucke, K. T. 1999, "Outcomes of nurse caring as perceived by individuals with spinal cord injury during rehabilitation", *Rehabilitation Nursing*, vol. 24, no. 6, pp. 247-253.	**Ref No**	NO.126
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Spinal cord injury**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Study conducted in the USA, on patient outcomes achieved during rehabilitation from the perspectives of 22 persons with SCI (16 males, 6 females), mean age 44; IVs took place 2weeks to 6 months after injury at two rehabilitation centres in Pennsylvania.
Findings relate to outcomes or 'consequences or nurse caring':
'getting back together' as a person – feeling 'more than a head' nurse enabling patient to become a whole person again
'lifting my spirits' – jollying the patient along – pointing out improvements
taking care of my body – teaching patient how to care for self
taking charge – patient getting back in control of own life
becoming independent
gaining hope

Reference	Post, M. W., van Asbeck, F. W., van Dijk, A. J., & Schrijvers, A. J. 1997, "Services for spinal cord injured: availability and satisfaction", *Spinal Cord*, vol. 35, no. 2, pp. 109-115.	**Ref No**	NO.127
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 T2 **T3** T4		
Location of study	UK **Other**		
Long Term Condition	**Spinal cord injury**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Study conducted in the Netherlands on services for SCI patients; availability and satisfaction. It is noted that Netherlands is wealthy country – all surveyed had access to domestic adaptations and wheelchairs regardless of income and with low or without user contributions. Surveyed 381 patients between 18-65 years at a mean time of 3.6 years after injury. Findings include:

Presence of domestic adaptation is high and 78.3% said their houses were sufficiently adapted at the time of the IV.

Wheelchairs are generally available and most patients had more than one but many users had complaints about them; 35.9% about manual wheelchairs and 47.5% about their electric wheelchairs.

Public transport was rarely used, 51.5% of patients had an adapted car

Satisfaction with services was acceptable but satisfaction with service delivery was very low

Satisfaction with available services did have a significant relationship with functional health status when the influence of the type of injury was taken into account.

Satisfaction with available services also had a significant relationship with life satisfaction after the influence of functional health status was taken into account.

Reference	McAlonan, S. 1996, "Improving sexual rehabilitation services: the patient's perspective", *American Journal of Occupational Therapy*, vol. 50, no. 10, pp. 826-834	**Ref No**	NO.128
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 T2 **T3** T4		
Location of study	UK **Other**		
Long Term Condition	**Spinal cord injury**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Study of 12 (10 male 2 female) SCI patients' access to sexual rehabilitation services. Age range 25-48 and length of time since injury from 1.6 to 12.4 years. Average time spent in rehabilitation was 3.7 months. Eleven were sexually active before injury, nine reported some sexual activity since time of injury. Eleven reported receiving some sexual rehab service, average 6 hours. The participants expressed views on the quality of sexual rehabilitation received. Six reported dissatisfaction with at least one aspect, two were neutral and four rated them as satisfactory for the following reasons:

Two reported discomfort during group presentations – individual sessions should be offered

Information received (content) generally helpful although only 3 reported that quantity was satisfactory

Direct, open style of presentation preferred by participants, however, timing must be addressed carefully – not all post-injury patients were ready to discuss sexuality; some reported still working on 'their attitudes to disability'.

Fertility and parenthood appears to (still) be a fraught area with insufficient information for those who want to pursue it. They are seen here as a 'major concern' of patients.

Reference	Nosek, M. A. 1993, "Personal assistance: its effect on the long-term health of a rehabilitation hospital population", *Archives of Physical Medicine & Rehabilitation*, vol. 74, no. 2, pp. 127-132.	**Ref No**	NO.129
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 T2 **T3** T4		
Location of study	UK **Other**		
Long Term Condition	**Spinal Cord Injury, Brain Injury and Stroke**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Study of personal assistance and its effect on the long-term health of a rehabilitation hospital population. Interviews with 41 physicians, physical therapists, OTs, social workers and nurses in 5 rehabilitation hospitals in the US. Key points:
A positive relationship was found between the adequacy of personal assistance and the ability of individuals disabled primarily by stroke, SCI or traumatic brain injury to maintain good physical and mental health.

The most commonly cited health problem was skin breakdown, followed by urinary tract infections, pulmonary infections and contractures.
Inadequate personal assistance also led to extended hospital stays, threats to safety, poor nutrition and poor personal hygiene.
Reliance on family alone was considered inadequate, common adverse effects including burnout, family role changes and economic strain.
Persons with the best health combined assistance by relatives and unrelated persons
Recommended is the establishment of a comprehensive system capable of co-ordinating service delivery from home health agencies, independent living centres and rehabilitation hospitals.

Unavailability of personal assistants was mentioned by 37% of sample.
Inadequate personal assistance compounds the consequences of primary disability and enables to occurrence of numerous physical and mental health conditions and secondary disabilities. Half the sample (51% indicated this is a severe to a very severe problem. Other conditions (to those above) cited include circulatory problems, bowel problems, regressed functional skills and physical deconditioning – due to inactivity (no exercise) lack of medication – inability to shift weight, psychological complications include depression and lack of motivation. Lack of PA also creates difficulties using and maintaining adaptive equipment.

Reference	Mercer, B. S. 1996, "A Randomized Study of the Efficacy of the PROPATH Program for Patients with Parkinson Disease", *Archives of Neurology*, vol. 53, no. 9, pp. 881-884.	**Ref No**	NO.130
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Parkinson's Disease**		
Confidence Rating	**Medium** – sample may not be representative of population of patients with Parkinson disease (attitudes + receptiveness to propath)		

Key points relating to user's experiences/views of (health or social care) services

Aims: to assess,

The effects of a health management program (PROPATH) on perceived general health, psychological well-being, & satisfaction with medical care
Utilisation of resources by patients with Parkinson Disease
Physician impression of the health program

Conclusions:

Patients enrolled in PROPATH, for 1 year, experienced improvement in perception of general health and psychological well-being compared to patients treated in usual way.
Lead to patients' reduction in days of fatigue and decrease in psychological distress.
Enrolment in the PROPATH program had no significance on patients' satisfaction with medical care
Significant reduction in patients' visits to physician or hospital
Majority of physicians did not find PROPATH helpful to development of treatment plan, management of the illness, identification of problems sooner [than by usual treatment], or identification of drug side effects
PROPATH has a useful role in assisting patients in their perception of their whole psychological well-being and general health.

Reference	Multiple Sclerosis Society 6666, *'Square pegs round holes': Does the system deliver for people with changing or hidden disability?* Multiple Sclerosis Society, London.	**Ref No**	NO.131
Research methods	Quantitative Qualitative **Mixed** √ Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

Research into flexibility in provision of social care services and benefits.
Methods: 3 discussion groups involving people with MS; findings used to design a questionnaire sent to 4000 MS Society members. 42% response rate to questionnaire**.**

Key findings:

There is a need for more frequent and improved communication between people with MS and providers of social care.
Services do not respond well to the fluctuating and often hidden nature of MS in some people. Needs are not met. This is especially true of DLA services.
Only a minority of people with MS have a key worker.
Counselling services have been used by only 9% of people with MS.

Recommendations:

Key workers are needed as a point of contact when needs change.
Clients should be offered annual reviews to maintain contact.
Greater awareness of fluctuating and hidden disability is needed, particularly among DLA assessors.

Reference	Multiple Sclerosis Society 2001, *Understanding Social Services: Getting the best for people with multiple sclerosis: A briefing for MS Society Regions and Branches in England and Wales* Multiple Sclerosis Society, London.	**Ref No**	NO.132

Research methods	Quantitative	Qualitative	Mixed	**Other**
Typology	**T1**	T2	T3	T4
Location of study	**UK**	Other		
Long Term Condition	**Multiple Sclerosis**			
Confidence Rating	High	Medium	**Low**	

Key points relating to user's experiences/views of (health or social care) services

This is a briefing paper produced for MS societies to help them and their members to understand the workings and responsibilities of social services departments in order that they might access the full range of benefits and services on offer. No user views are sought and no experiences described.

Reference	Birleson, A. 2001, *An Evaluation of Service Need and Availability for the Younger Person with Parkinson's Disease* Institute of Rehabilitation, Newcastle upon Tyne.	**Ref No**	NO.133
Research methods	Quantitative Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Parkinson's Disease**		
Confidence Rating	High Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Users report consultants do not refer them appropriately to other professionals

Users report infrequent monitoring from therapists

Users felt they needed more advice on medication and lifestyle issues relating to the disease

Users identified a range of physical symptoms but were unsure if these needed professional intervention, suggesting a lack of understanding on the roles and services provided

Respite care is viewed negatively

Despite identifying a desire to maintain social activities users didn't se this as an area requiring specialist intervention

None of the users in this study were employed, all having given up work due to their condition and all felt some 'sense of failure'.

Users report that intervention is usually only at times of crisis and are unhappy with this, identifying self-referral as a useful option, especially as many professionals agree that late referral means that problems are more difficult to deal with at that stage.

Users report feeling 'abandoned' between consultant appointments (usually between 6-12 months).

Users report lower quality of life due to lack of services

As a group Parkinson's Disease sufferers are well able to say what a service should look like.

Reference	Chesson, R., Cockhead, D., & Romney-Alexander, D. 1999, "Quality of life with Parkinson's disease: views of Scottish consumers and providers," in *Parkinson's Disease: Studies in Psychological and Social Care*, R. Percival & P. Hobson, eds., British Psychological Society, Leicester, pp. 93-130.	**Ref No**	NO.134

Research methods	Quantitative	Qualitative	**Mixed**	Other
Typology	T1	**T2**	T3	T4
Location of study	**UK**	Other		
Long Term Condition	**Parkinson's Disease**			
Confidence Rating	**High**	Medium	Low	

Key points relating to user's experiences/views of (health or social care) services

Book chapter that reviews two linked studies on PD patients' expectations of and satisfaction with health care (therapies), and quality of life.

Study 1 - availability of therapy services (physiotherapy, OT, speech therapy). Questionnaire surveys (PD Society members, staff groups) and interviews. 665 completed questionnaires returned by people with PD.

Study 2 - health-related quality of life. Qualitative interview study. Included interviews with patients (30) with PD.

Questionnaire findings:

Half of those with PD had received therapy of some kind.

82% thought therapy services could be requested when needed, usually via GP.

Interview findings - health- related quality of life:

Reports patients' evaluations of aspects of their quality of life.

Patients commented on the essential role played by medication in QOL, but service experiences in this regard are not reported.

Use of therapy services and day hospitals: Most patients thought their therapists did have an understanding of their PD problems, but a small minority were critical on this. Lack of continuity of care was reported by some. A majority thought that therapy was beneficial. Some valued the social aspect of therapy.

Reference	Jones, R., D'eath, C., Harnsford, J., Hutchinson, H., Hyde, L., Thurlow, L., & Spanton, L. 1999, "The needs of people with Parkinson's disease and their families: The Parkinson's Disease study, Devon and Cornwall, 1989-92," in *Parkinson's Disease: Studies in Psychological and Social Care*, R. Percival & P. Hobson, eds., pp. 60-78.	**Ref No**	NO.136
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Parkinson's Disease**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Sufferers report that the diagnosis is not well handled by GPs or specialists

Ongoing communication with professionals is similarly rated

The majority of the sample did not know about other available services (e.g. respite care)

Suffers tend to under-report symptoms (especially feelings of depression)

Reference	Essex Coalition of Disabled people & SCOPE 2003, *The Good Practice Guide for support workers and personal assistants working with disabled people with communications impairments*.	**Ref No**	NO.138
Research methods	Quantitative Qualitative Mixed **Other** A guide written for support workers and PAs by disabled people		
Typology	T1 T2 **T3** T4		
Location of study	**UK** Other		
Long Term Condition	**Specifically about people who have language but don't use speech.** (Could include some of those with the target medical conditions)		
Confidence Rating	**High** Medium Low I'm confident it was produced by service users in the group above, and that it reflects their view of how they would like support workers to treat them. Its not about evaluating services but rather trying to shape them.		

Key points relating to user's experiences/views of (health or social care) services

Communication difficulties for this group are linked to impairment but the greater part of their difficulties are caused by 'speaking' people not having the experience, time or commitment to trying to understand and be inclusive.

Communication is a human right. Communication assistance is essential for full citizenship.

Disabled people in this group have a range of communication strengths and styles. Signing probably not needed unless there is some hearing impairment.

Many are affected by fatigue so strengths may vary as the day goes on.

Development of hi-tech aids (equipment?) and IT is welcome. However they can be a pain to use and getting them fixed can be a hassle. Low-tech communication aids are useful but people also may want to use body language, sounds, eye pointing and the like.

Good facilitation: someone who knows us (without being stuck in a rut); respect, equal treatment; accepts responsibility for delivering the right to communicate; uses their own skills; interprets exactly what is said; sensitive to the kinds of communication appropriate in different situations; keeps on consulting the user.

Poor facilitation: not being prepared to take time or persevere; taking over in communication with others; acting as if you weren’t there; talking about you.

Tips for communication
Find out what people prefer
Slow down and listen
Pay attention to body language and facial expression
Eye contact and right physical position
Don’t be afraid of sounds or movements
Spend time getting used to preferred methods – best somewhere quiet
Believe that you will understand
Check out you’ve interpreted right
Tell others to communicate directly (unless another strategy agreed)
Be assertive about the right to communicate
Help with choices
Respect privacy

Reference	Lamb, B. & Layzell, S. 1994, *Disabled in Britain: A World Apart* SCOPE, London.	**Ref No**	NO. 140
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 T2 **T3** T4		
Location of study	UK **Other (USA)**		
Long Term Condition	**Cerebral Palsy; General**		
Confidence Rating	High Medium **Low** – mainly because so little info on methods given		

Key points relating to user's experiences/views of (health or social care) services

Problems in getting aids and adaptations installed in own home, so can move around easily.

Inadequate support in the community. Services pay scant regard to people's needs, but owe more to the assumptions of those providing the services.
Little control over how services are delivered.

Difficult to get information re services needed. Respondents valued info being provided in a context where emotional or other support could follow, hence the popularity of friends and charities.

Respondents had impression that professionals do not really listen to them, but base decisions on pre-conceived assumptions.

Feel that their views are not taken into account; doctors do not listen to what respondents say or talk to carer rather than them.

Feel that assessments are humiliating as designed to explore incapacity rather than ability.

Feel that whether or not services are provided depends on resources available and not their needs.

18% respondents had to refuse a service as could not afford it – home help service specifically mentioned as one where extra charges have led to disabled people being forced to forego service.

May not be able to get small items through statutory services and cannot afford to buy them. Unable to obtain larger items such as appropriate wheelchairs or housing adaptations.

Delays getting funding for adaptations from social services to make housing suitable.

Reference	Lamb, B. & Layzell, S. 1995, *Disabled in Britain: Counting on Community Care* SCOPE, London.	**Ref No**	NO.141
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 T2 **T3** T4		
Location of study	**UK** Other		
Long Term Condition	**General (Disabled Adults)**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Presents research undertaken for SCOPE in 1994. 1,568 disabled and 1,324 carers completed postal questionnaires. The Research has also been published at Disabled in Britain: A World Apart and Disabled in Britain: Behind Closed Doors.

Three main 'recurring problems' encountered when using health and social services

1. Service Provider's attitudes, professionals often patronising, treating disabled people as vulnerable and in need of protection resulting in decisions being made without their full participation
2. Poor communication between providers and users of services both in terms of information provision and the listening ability of professionals and statutory organisations.
3. Poor physical access to health and social care settings

Satisfaction with services
Medical care – Doctors most highly praised of all medical professionals. GPs have a key role in disabled people's lives because of the gatekeeping function they serve especially to services and benefits.
89% satisfied with service provided by hospital doctors/consultants
Two main areas of concern

1. diagnosis of acquired impairment
2. validation of symptoms (psychological benefits/gateway to services/benefits)

Other health services
Generally dissatisfaction relates to inadequate provision of services. Many respondents felt they would benefit from increased service inputs especially physiotherapy, and speech therapy.

Social Care Provision

Again dissatisfaction tends to relate to lack of resources. Many believe inadequate funding reflects low priority attached to disabled people.

Equipment and Adaptations

Failure to provide appropriate equipment is short sighted (promoting of independence/preventing residential care)

Many community care service users are satisfied with particular services but extremely unhappy with aspects of the system such as inadequate/insensitive assessment, inadequate service provision (esp. respite care) and charging. The disruption caused by reorganisation and changing patterns of services.

Reference	Yarrow, S. 1999, *Survey of Members of the Parkinson's Disease Society* Parkinson's Disease Society/Policy Studies Institute, London.	**Ref No**	NO.143
Research methods	**Quantitative** Qualitative Mixed Other Postal questionnaire sent to random sample of 10%of members. The response rate was 68%. The survey closely mirrored the Oxtoby Report which was undertaken in 1979, findings were compared were possible.		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Parkinson's Disease**		
Confidence Rating	High **Medium** Low The methodology appears sounds however findings are limited by tick box answers. No real attempt to collect service user's opinions		

Key points relating to user's experiences/views of (health or social care) services

The report provides details about the membership of the Parkinson's Disease Society – 2/3 had Parkinson's, 12% carers, 10% former carers, 3% professionals (mainly health professionals). The majority of the questionnaire was answered by all PDS members however there was one section was for people living with PD and one for carers.

The nature of the questionnaire meant that the majority of information presented in the report is quantitative and related to functioning, experience of symptoms and services used with tick boxes provided for answers. The only questions solely directed at people living with PD that allowed them to provide a more detailed answer were in respect of what (apart from medical treatment) was felt to be need most of all at the moment. Issues such as accessing public transport, environmental barriers, low income were raised.

A large section of the questionnaire and report was devoted to members experiences of the PDS, which raised the importance of information most frequently about medical subjects.

Reference	Wenneberg, S. & Ahlstrom, G. 2000, "Illness narratives of persons with post-polio syndrome", *Journal of Advanced Nursing*, vol. 31, no. 2, pp. 354-361.	**Ref No**	NO.145
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Polio**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

This study involved qualitative interviews with 15 individuals (interviewed twice) experiencing the late effects of polio. Narratives were gathered on the lifetime experience of polio and its aftermath.

With regard to service experiences, the focus is on these individuals' memories of health services encountered when they contracted polio in childhood. The narratives presented indicate that these respondents had extremely unhappy and psychologically disturbing experiences of health and social care services some 50 years ago (isolation hospitals and residential institutions for disabled children with brutally strict regimes and harsh treatments).

The paper highlights the ways in which these individuals 'overcame' their disabilities to live 'normal lives', but reports that disturbing memories sometimes returned.

Respondents were now living with the late effects of polio. The paper gives little attention to these users' current service experiences. The few points made indicate general satisfaction with services, with only one reference to being treated 'badly' by a doctor.

Reference	Bamford, D., Griffiths, H., Long, S., & Kernohan, G. 1997, "Analysis of consumer satisfaction in cerebral palsy care", *Journal of Interprofessional Care*, vol. 11, no. 2, pp. 187-193.	**Ref No**	NO.147
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2 but children only** T3 T4		
Location of study	**UK** (Northern Ireland) Other		
Long Term Condition	**Cerebral Palsy**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

NB this paper relates to children with CP and their families however it raises important generalisable issues.

The paper notes that the social implications of CP are infrequently studied despite 'social and emotional' disturbance in family life it can give rise to.

201 postal questionnaires, 73 returned (36%). 60 were analysed.

Interesting review of theoretical and policy context. Relevant points included:

- Recognises the 'endemic tensions and creativity of multi-disciplinary working' can have either positively or negatively on service users
- Danger of 'culture of professionalism' which negates user views
- Ross & Waterson (1996) 'listening to users' involves moving from reactive crises management to proactive crises prevention services.

Findings

Core medical help is good, actual surgery is excellent. Key paramedical professionals are highly thought of. (Surgeons, GPs, Hospital doctors, nurses, physios, teachers – credited most highly – other professionals ratings extremely varied).

If a concept of 'total care' (social, emotional and psychological needs) is adopted there are 'glaring deficiencies'
Skilled counsellors
Lack of support at crises points
Lack of coherence/integration between professionals especially when creating a

bridge between core medical needs and wider social needs

Reference	Bamford, D., Griffiths, H., & Kernohan, G. 1997, "On Patient Satisfaction in Cerebral Palsy Care", *British Journal of Social Work*, vol. 27, no. 4, pp. 605-614.	**Ref No**	NO.148
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Cerebral Palsy**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services
NB Report on a pilot study of randomly selected sample of families in Northern Ireland– based on 8 returned questionnaires from families with child affected by CP. Focus 'on the quality of care available to families as they attempt to cope with the social and emotional reality of CP' (p666). Age at diagnosis varied from 1-36 months.

Main findings are:
A genuine need expressed for more help and support especially during the first 4 months when parents are informed of the diagnosis of CP. Not enough carer support at this stage, no information available and no indication given of where to go for help (pp666/7).

Each professional group was 'scored' on scale (1 = excellent; 2=good, 3=poor and 4=none). This produced evidence of a variable quality of help from professionals. Doctors and teachers scored well. GPs get better scores than surgeons and other hospital doctors. Hospital nurses score highly in stake contrast to community based nurses who do very poorly (p608). Social workers score poorly – disappointing to authors 'given the social and emotional focus of the study' (p608).
Not one respondent ever received an information pack – all would have welcomed this facility

Strong and unresolved feelings of anger, hurt, guilt and blame evident in additional comments section.

Highlights need for **integrated support –** combining a specific medical or para-medical task with psychological /counselling help. Authors suggest this may be why nurses, physiotherapists, OTs, speech therapists and GPs score so solidly.
Type of help received as well as quality of help assessed. Ten of the thirteen types of help received got a mean score of not enough (3) or non-existent (4). 'Gross deficiencies in services are starkly revealed' (p608)

deficiencies in services are starkly revealed' (p608).
Also covered is 'relative accessibility of different types of help. Results indicate that with notable exception of support at crisis point, professional counselling and respite care – access to the remainder of services is possible, although determination and persistence are frequently required.
Parents very concerned about future needs and have a low expectation of help and a degree of anticipatory fear about more assistance required for the child as it develops.

Three out of 8 respondents said that there had been a crisis point when they felt they could no longer cope. 'Social workers, arguably the most appropriate trained professional group to offer such counselling are either not functioning at this level or not …accessible' (p613).

Medical explanations – about timing and reason for surgery rated very good, about complications of surgery rated good, orthopaedic care rated good, post-operative care rated fair as were general hospital facilities.

Users feel comparatively isolated – having 'very considerable reservations (pp613/4) about the quality of services they receive. Access to readily available high quality services is frequently elusive.

Quality of help scores for hospital social workers and health visitors barely rise above nought. All users had attended out-patients units with a well-established social work department – so authors claim this highlights need for more effective inter-disciplinary collaboration.

Need for skilled counselling to be made available at the point of crisis.
Families cope with many aspects of CP either alone or with support from family/ friends.

Reference	Kolakowsky-Hayner, S. A., Kreutzer, J. S., & Miner, K. D. 2000, "Validation of the service obstacles scale for the traumatic brain injury population", *Neurorehabilitation*, vol. 14: no. 3, pp. 151-158.	**Ref No**	NO.149
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other (USA)**		
Long Term Condition	Brain Injury		
Confidence Rating	High **Medium** The research itself appears robust however its findings represent the views of carers not service users. Low		

Key points relating to user's experiences/views of (health or social care) services

Despite traumatic BI being one of the leading causes of death and disability in the US limited access to specialist medical and rehabilitation services has been linked to poor outcomes. In 1997 the Service Obstacles Scale (SOS) was developed as an outcome measure in Virginia. The aim of the study was to examine the application of the SOS as a measure of state-wide service delivery. The SOS has three main components,: satisfaction with treatment resources, finances and transportation as obstacles to receiving services.

136 carers were surveyed by post.

Findings

Relatively few respondents viewed transportation as an obstacle to receiving services.
Many people were displeased with the adequacy of resources in the community
C 2/3 of respondents characterised themselves as happy with their quality of life but many reported dissatisfaction with the quality and availability of services.

Limitations

The study focused on the perceptions of care givers therefore "More information is needed about the perceptions of people with brain injury and the comparability of their perceptions with caregivers" (156)

Reference	Trail, M., Nelson, N., Van, J. N., Appel, S. H., & Lai, E. C. 2001, "Wheelchair use by patients with amyotrophic lateral sclerosis: A survey of user characteristics and selection preferences", *Archives of Physical Medicine & Rehabilitation*, vol. 82, no. 1, pp. 98-102.	**Ref No**	NO.151

Research methods	**Quantitative**	Qualitative	Mixed	Other
Typology	T1	T2	T3	**T4**
Location of study	UK		**Other**	
Long Term Condition	**General (neuromuscular)**			
Confidence Rating	High	**Medium**	Low	

Key points relating to user's experiences/views of (health or social care) services

A survey designed to find out what sort of patients would benefit most from what sort of wheelchair so NOT really relevant to this project.

For the record:

Motorized wheelchairs offer a greater sense of independence and improved feeling of well-being

Reference	Goldstein, L. H., Adamson, M., Jeffrey, L., Down, K., Barby, T., Wilson, C., & Leigh, P. N. 1998, "The psychological impact of MND on patients and carers", *Journal of the Neurological Sciences,* vol. 160, no. Supplement 1, pp. 114-121..	**Ref No**	NO.152
Research methods	**Quantitative** Qualitative Mixed Other But with very small numbers		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Motor Neurone Disease**		
Confidence Rating	High Medium Low Persons (with partners) attending Kings MND Care and Research centre. 43 asked, 19 agreed. Patient and partner asked to complete questionnaires and interviewed re their responses		

Key points relating to user's experiences/views of (health or social care) services

16 psychological scales administered. Results not reported here as none reflect views of services. Paper is about psychological impact on patients and carers related to things like length of time since onset and changes in functioning.

A few statistics on service use, but no info on views of services. They did ask for satisfaction ratings but don't report them except to say that carers ratings of their anticipated ability to cope in future correlated with their rating of satisfaction with services.

Reference	Johnston, M., Earll, L., Mitchell, E., Morrison, V., & Wright, S. 1996, "Communicating the diagnosis of Motor Neurone disease", *Palliative Medicine*, vol. 10, no. 1, pp. 23-34.	**Ref No**	NO.154
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Motor Neurone Disease**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

A study examining the communication of the diagnosis of MND to patients.

Participants found that….

- Having a label was generally felt to be a good thing with coping mentioned as a way of responding to the diagnosis.
- An audio tape of the diagnostic interview was favoured by individuals with relatively better prognosis, but not by those who were given a poor prognosis.
- Almost half the participants did not understand the diagnosis
- The most common complaint was of being told the diagnosis in vague terms
- Some participants were alone when they received the news and would have felt better with a family member present
- Some participants were given the diagnosis in a situation that lacked privacy
- Some participants wanted more information at the time, particularly in relation to finding out more about the disease

Reference	Mukai, M., Uchimura, N., Takeuchi, N., Kuwahara, H., Hashizume, Y., Nose, I., Satomura, T., Tanaka, J., & Maeda, H. 2001, "Study on withdrawal of hypnotics: Questionnaire on hypnotic use and its withdrawal", *Psychiatry & Clinical Neurosciences*, vol. 55, no. 3, pp. 209-210.	**Ref No**	NO.159
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 T2 T3 **T4**		
Location of study	UK **Other**		
Long Term Condition	**General**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

User experience of hypnotics is reported in purely statistical form, from a 75% response rate to a questionnaire. Any 'evidence ' is inconclusive.

- Half of the respondents wanted further information from the doctor regarding their medication (?and half didn't)
- 53% took hypnotics regularly
- 27% stopped taking their medication without consulting the doctor . 'more than half' of these reported trouble sleeping.

Reference	Taylor, D. C., McMackin, D., Staunton, H., Delanty, N., & Phillips, J. 2001, "Patients' aims for epilepsy surgery: Desires beyond seizure freedom", *Epilepsia*, vol. 42, no. 5, pp. 629-633.	**Ref No**	NO.160
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Epilepsy**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Study evaluated prospectively patient's aims for epilepsy surgery. Methods – 93 consecutive patients were interviewed by a psychiatrist as part of their evaluation for epilepsy surgery. Open-ended questions about the patient were asked and carer's aims or ambitions for change as a result of putative relief of seizures were elicited. Interviewer aimed to obtain a maximum of 5 aims for later follow up study.

The aim of 69 patients or carers were analysed. The 204 statements of aims were grouped into 59 categories initially. The five most frequently cited constituted 50% of all of the aims listed. These aims were:

- Desire for work
- Driving of motor vehicles
- Independence
- Socializing
- Freedom from drugs

Patients rarely identified a desire for improvement in cognitive functioning as an aim for epilepsy surgery. A final analysis into six categories showed changes in social process predominated, even over changes in personal behaviour

Authors conclude:

- Social and personal aims to accompany relief of epilepsy identified by patients are consistent with the literature on psychosocial adjustment to epilepsy

Reference	Fisher, R. S., Vickrey, B. G., Hermann, B., Penovich, P., Scherer, A., & Walker, S. 2000, "The impact of epilepsy from the patient's perspective II: Views about therapy and health care", *Epilepsy Research*, vol. 41, no. 1, pp. 53-61.	**Ref No**	NO.162
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other** Arizona USA		
Long Term Condition	**Epilepsy**		
Confidence Rating	High **Medium** Low Postal survey. Achieved sample 1023. (49% response rate). Refers to “companion paper” for methodology.		

Key points relating to user’s experiences/views of (health or social care) services

68% were very (or extremely) satisfied with current medication.

Inter-individual differences in side effects of concern suggest medication choices should be individualised according to potential side effects and users evaluations of them. Heightens importance of information re possible side effects necessary as a basis for choosing most suitable medication in individual case.

Key complaints inadequate time for medical providers to answer questions…. And lack of accessible information. Many wanted more information about epilepsy.

Physician characteristics appreciated by people with epilepsy: caring, compassionate, available to answer questions; able to choose the right medication; knowledgeable; up to date; optimistic; tenacious; cautious about medication changes and able to work in concert with patients and general physicians.

Rank order (starting highest) of important areas re medication: seizure control; fewer side effects; convenient dosing regimen; costs.

Adverse medication effects, ranked (between 40 and 20% reporting each as having a large effect): problems with cognition; energy levels; school performance; childbearing; coordination and balance; sexual function.

Reference	Wass, C. T., Rajala, M. M., Hughes, J. M., Sharbrough, F. W., Offord, K. P., Rademacher, D. M., & Lanier, W. L. 1996, "Long-term follow-up of patients treated surgically for medically intractable epilepsy: Results in 291 patients treated at Mayo Clinic Rochester between July 1972 and March 1985", *Mayo Clinic Proceedings*, vol. 71, no. 11, pp. 1105-1113.	**Ref No**	NO.171

Research methods	**Quantitative**	Qualitative	Mixed	Other
Typology	T1	**T2**	T3	T4
Location of study	UK	**Other**		
Long Term Condition	**Epilepsy**			
Confidence Rating	**High**	Medium	Low	

Key points relating to user's experiences/views of (health or social care) services

- Study to assess long-term outcomes of patients who underwent surgical treatment for intractable epilepsy by reviewing medical records of 291 patients between 1972 and 1985. Also evaluated the responses to a follow up mailed questionnaire or telephone interview completed in 1992.
- Of the 291 patients, 245 responded.
- Information on the patients' neurological status (including frequency of seizures, use of antiepleptic drugs and self-reported assessment of functional capacity and overall satisfaction with the operative procedure and postoperative outcome were evaluated.
- 290 patients survived the operation. Of the 245 patients who responded to the follow up survey 41% and 58% had been free of seizures since surgical treatment and/or 3 years preceding the follow un survey respectively.
- 36% of patients were successfully weaned off all anti-epileptic drugs
- Patients reported improvement is daily functioning and quality of life after surgery
- Patients ability to obtain driving life significantly increased
- 85% reported they would repeat the operative procedure.
- Conclude that surgical treatment of intractable epilepsy is an effective option that is met with patient satisfaction.

Reference	Sparber, A. & Wootton, J. C. 2002, "Surveys of complementary and alternative medicine: Part V. Use of alternative and complementary therapies for psychiatric and neurologic diseases", *Journal of Alternative & Complementary Medicine*, vol. 8, no. 1, pp. 93-96.	**Ref No**	NO.182
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	High Medium Low		

Key points relating to user's experiences/views of (health or social care) services

This is a summary of four surveys of psychiatric patients seeking to establish the relationship between patient depression and the willingness to use complementary and alternative medicine. No user views are provided.

Reference	Vickrey, B. G., Edmonds, Z. V., Shatin, D., Shapiro, M. F., Delrahim, S., Belin, T. R., Ellison, G. W., & Myers, L. W. 1999, "General neurologist and subspecialist care for multiple sclerosis: Patients' perceptions", *Neurology*, vol. 53, no. 6, pp. 1190-1197.	**Ref No**	NO.183
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other (USA)**		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	**High** (taking into account differences between the US/UK health care system Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Aim of study was to compare the impact of having a general neurologist versus an MS specialist on patients clinical characteristics and MS care as perceived by patients. The research was undertaken in 1996 in the American Mid West. 694 postal questionnaires were circulated with a response rate of 77%.

Findings

94% of respondents usual physician was a neurologist, of this 43% had a general neurologist and 57% a MS specialist.

There were no real differences in patient characteristics and many aspects of recent medical care, use of services and unmet needs between the two groups

MS specialists may have had more experience in the use of and advice to patients about new treatments and management of side effects, better perceptions by patients on communication issues and higher involvement of patients in some types of research and access to MS care in some areas.

Similar proportions of each group had taken Interferon but patients with a specialist neurologist were more likely to be currently taking it whereas patients in the generalist group were more likely to have desisted due to side effects. This may well be due to specialist neurologists greater knowledge and expertise in MS specific medication.

Reference	Rumrill, P. D., Jr., Roessler, R. T., & Koch, L. C. 1999, "Surveying the employment concerns of people with multiple sclerosis: A participatory action research approach", *Journal of Vocational Rehabilitation* , vol. 12, no. 2, pp. 75-82.	**Ref No**	NO.184
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	**T1** T2 T3 T4		
Location of study	UK **Other** (USA)		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Results of the employment concerns reported by a random sample (n=227) people with MS. Members of MS Society identified 34 employment concerns as most reflective of the career development implications of MS. Survey respondents considered each item along two dimensions, the importance of the item to career development and their satisfaction with the adequacy of services that address that concern. Findings include:

- Results regarding high importance items indicated respondents were most satisfied with issues such as health insurance coverage, p [potential to work and take control of their lives, wages and benefits and workplace accommodations
- Most dissatisfied with issues including fair treatment by employers and hiring process, access to service providers who understand their needs, access to adequate information about social security programs, optimism regarding their future and issues related to re-entering the workplace. Implications for vocational rehabilitation practice and future research discussed

NB Participatory Action Research used

Reference	Critchley, G. R. & Richardson, P. L. 1998, "Vim thalamotomy for the relief of the intention tremor of multiple sclerosis", *British Journal of Neurosurgery*, vol. 12, no. 6, pp. 559-562.	**Ref No**	NO.185

Research methods	**Quantitative**	Qualitative	Mixed	Other
Typology	T1	**T2**	T3	T4
Location of study	**UK**	Other (USA)		
Long Term Condition	**Multiple Sclerosis**			
Confidence Rating	**High**	Medium	Low	

Key points relating to user's experiences/views of (health or social care) services

- Study reviewed outcomes of patients who had undergone thalamotomy for the intention tremor of MS. 24 patients underwent 29 procedures between 1988 and 1995
- Mixed results of procedures. 23% reported improvement in arm function
- Out of 23 patients, four were enthusiastic, and 10 satisfied with outcome
- No other user views

Reference	Jongbloed, L. 1998, "Disability income: The experiences of women with multiple sclerosis", *Canadian Journal of Occupational Therapy*, vol. 65, no. 4, pp. 193-201.	**Ref No**	NO.186
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 T2 **T3** T4		
Location of study	UK **Other (Canada)**		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Paper is based on a subset of findings from a larger qualitative and quantitative study on employment and women with MS: interviews with 23 women no longer in employment that focused on accessing disability benefits and living with the constraints imposed by those benefits.

Relevant Findings:

- Benefits determined by eligibility criteria assessed by a physician. The nature of MS symptoms makes this problematic, particularly invisible or hard to measure symptoms such as fatigue. Claims by people with MS are subject to higher levels of scrutiny than other impairment groups.
- Basic level of benefits severely curtail a range of activities from having a healthy diet to social activities. For one woman her OT failed to address how she could cope living on a reduced income, the focus was on climbing stairs and conserving energy.
- The unpredictable nature of MS meant that once eligibility for benefits had been established the women were afraid to return to work and risk losing their financial security,.

Implications of Occupational Therapy

- OT interventions can occur at the individual or larger social, economic and political level and "demands an awareness that individual experiences are interwoven with social structures; and that the choices women make about how they will spend their time are contingent of the social context in which they find themselves"
- Townsend (1993) - Occupational Therapy's vision is to promote social justice.

Reference	Aronson, K. J., Cleghorn, G., & Goldenberg, E. 1996, "Assistance arrangements and use of services among persons with multiple sclerosis and their caregivers", *Disability & Rehabilitation*, vol. 18, no. 7, pp. 354-361.	**Ref No**	NO.188
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other/Canada**		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Method

'self-completed mailed questionnaires' 697 people with MS & 345 carers (response rates of 83% and 72%)

Findings

The paper provides tabular reports of the type of assistance required as well as duration of assistance.

The research highlights the 'tremendous reliance' on family caregivers. Available respite care is underutilised (reasons not discussed).

Prolonging home care and postponing early institutionalisation was a high priority.

The findings in this paper are more relevant to the second stage of the study as it details the relationship between recipient and care-giver

Reference	Gulick, E. E., Cook, S. D., & Troiano, R. 1993, "Comparison of patient and staff assessment of MS patients' health status", *Acta Neurologica Scandinavica*, vol. 88, no. 2, pp. 87-93.	**Ref No**	NO.190
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Study compared change scores obtained on patient self-reported symptoms with the neurological examination of the Kurtzke Functional Systems and change scores obtained on patient self-reported activities of daily living with the neurologist determined Expanded Disability Status Scale –100 patients with MS.

Main argument is that using patient self report scales (patient perspective) can be useful in guiding the physical examination, in making comparisons from visit to visit and in assessing patient's quality of life and increasing patient satisfaction with medical care.

Reference	Bennion, E. 2002, "Commentary: The freedom of informed choice", *British Medical Journal*, vol. 325, p. 1169.	**Ref No**	NO.192
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Parkinson's Disease**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

Commentary (rhetorical) by person with PD whose drugs 'suffered at the hands of the regulators'. The drug (tolcapone) relieves the on/off state of PD and subsequently improves mobility and function and was launched in Britain in 1997. The drug was withdrawn in Europe in 1998 after a few reports of severe hepatoxicity (toxic effects on liver). Bennion's functioning level dropped dramatically. The main point made is that many people make informed choices over taking certain drugs (e.g. contraceptive pill) that have some inherent risk to health. Bennion felt denied the opportunity to exercise this choice by the actions of the regulator. Now obtains the drug privately at a high cost (£450 every 3 months). Other points made include:

- Healthcare professionals and policy makers need to understand that their own perceptions of health may differ from those of their patients.
- Patients need to become empowered to take control of their illness and so ensure that it does not impair their quality of life.
- Patients have knowledge and experience and a desire to manage their own condition and these three factors should be harnessed to ensure that resources are used wisely and service provided appropriately
- Patients with long term conditions should have the right to make informed choices on issues such as whether to take part in drug trials and on the pros and cons for a particular treatment and its adverse effects.

Reference	Trend, P., Kaye, J., Gage, H., Owen, C., & Wade, D. 2002, "Short-term effectiveness of intensive multidisciplinary rehabilitation for people with Parkinson's disease and their carers", *Clinical Rehabilitation*, vol. 16, no. 7, pp. 717-725.	**Ref No**	NO.193
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Parkinson's Disease**		
Confidence Rating	High **Medium** (robust methodology however paper recognises projects 'drawback' was the one-off nature of the intervention Low		

Key points relating to user's experiences/views of (health or social care) services

Rationale

Little robust research-based evidence exists in support of the importance of nonpharmacological approaches to the management of PD. This study aimed to investigate the impact of multidisciplinary rehabilitation and a supportive group programme of education (on mobility/functional independence, awareness of speech problems/ability to deal with these problems, psychological well-being/health-related quality of life).

Methods

137 patients recruited, 118 (86%) proceeded to treatment
Patients and carers were assessed using a variety of measures (some assessed by specialist nurse, speech therapist, physiotherapist, care manager, independent researchers and self-assessment).

Generalisability

Cognitively impaired people with PD were not recruited by in other respects the sample was similar to other recent UK studies.

"By focusing on the practical problems associated with Parkinson's disease in their everyday lives, it broke down discipline-based demarcations. It recognised the importance of multiple professions for addressing the variety of problems experienced by people with PD. By providing a blend of tailored individual therapy and group social and educational activities, it offered practical help, information and support to patients and carers, and motivated self-care" (723)

Clinical messages

- Intensive multi-disciplinary rehabilitation for people with PD and their carers results in immediate improvements in patients mobility, speech, depression and health-related quality of life, but no change in carer wellbeing
- Assessment reveal some unmet need for social services and carer strain

Reference	Ryan, M., Johnson, M. S., Dalmady-Israel, C., & Kaiser, J. M. 2002, "Use of alternative medications in patients with neurologic disorders", *Annals of Pharmacotherapy*, vol. 36, no. 10, pp. 1540-1545.	**Ref No**	NO.194
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 T2 T3 **T4**		
Location of study	UK **Other**		
Long Term Condition	**General (neurological conditions)**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

A study designed to determine and predict use of complementary and alternative medicines (CAMs) in patients attending a neurological clinic. **No user perspective is offered.**

One interesting point emerges
'Most patients were undecided about the efficacy of the alternative medications'

Reference	Williamson, C. 2001, "What does involving consumers in research mean?" *Qjm: Monthly Journal of the Association of Physicians*, vol. 94, no. 12, pp. 661-664.	**Ref No**	NO.195
Research methods	Quantitative Qualitative Mixed **Other** **Editorial comment reviewing literature**		
Typology	T1 T2 T3 **T4** Author is Chair of Consumers for Ethics in Research (CERES) – not clear if this user-led		
Location of study	**UK** Other		
Long Term Condition	**General**		
Confidence Rating	High Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Discusses what '*involving consumers in research'* might mean. Author is Chair of Consumers for Ethics in Research (CERES) – not clear if this user-led
'Consumers' very broadly defined to include *"patients, past patients, prospective patients, long-term users of health care services, relatives caring for patients or users, and people who speak for these primary consumers through local and national support and activist groups, community organisations such as community health councils, local and national coalitions of such groups and international networks*"

Consumerism is "*a voice speaking for the perspectives, ideas, interests and values of patients, users and carers as they define them*" *(my emphasis)*.

Distinguishes between consultation (gives users a voice but not decision making role) and partnership (shared decision-making, requires support to ensure no one is excluded), and raises.

Main points
Health professionals often uncertain about which consumers to involve
Need to distinguish between personal insights of individual patients and 'units of collective knowledge'
Importance of appointing several consumers to any group to prevent tokenism and to create partnership
Need for open advertisements and transparent procedures when inviting consumers to participate
Partnership requires consumers to be involved from the first
Importance of supporting consumers – in accessing professional literature but also consumer perspectives – task can be onerous 'Time knowledge and effort have costs'

Reference	Barber, M., Stewart, D., Grosset, D., & MacPhee, G. 2001, "Patient and carer perception of the management of Parkinson's disease after surgery [2]", *Age & Ageing*, vol. 30, no. 2, pp. 171-172.	**Ref No**	NO.196
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2 *** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Parkinson's Disease**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Users report high dissatisfaction with peri-operative management

94% (n=16) complained of confusion or worsening of their condition post- operatively

users suggest that medication administration problems are common

the data referred to here are reported via a letters page though they are no less valid for that. The questionnaire was designed to elicit information on in-patient treatment requiring G.A.

Reference	Rubenstein, L. M., Voelker, M. D., Chrischilles, E. A., Glenn, D. C., Wallace, R. B., & Rodnitzky, R. L. 1999, "The usefulness of the functional status questionnaire (FSQ) and the medical outcomes study short form (SF-36) in Parkinson's disease research", *Mature Medicine Canada*, vol. 2, no. 1, pp. 44-48.	**Ref No**	NO.197
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other (USA)**		
Long Term Condition	**Parkinson’s Disease**		
Confidence Rating	High **Medium, methodology appears robust but no user views obtained as part of research** Low		

Key points relating to user’s experiences/views of (health or social care) services

Health Related Quality of Life (HRQL) measures makes information about patients functional status, general health perceptions and satisfaction with health and well-being available and provide important information from the patients perspective and reflect what is crucial and significant to their PD treatment and daily lives.

Method

Cross-sectional survey of patients from a range of hospitals across Iowa. A Research Nurse administered narrative and physical evaluations and recorded condition related information. Patients completed a ‘take-home questionnaire”.

Findings

- The measures can be self-administered and do not require a trained interviewer. High response rates indicates patients are happy to answer questions about their health perceptions.
- Pertinent information was provided by health profile measures that standard clinical instruments would not obtain.
- The article does not present any patient views on the use or applicability of the measures

Reference	Vaidyanathan, S., Glass, C. A., Soni, B. M., Bingley, J., Singh, G., Watt, J. W. H., & Sett, P. 2001, "Doctor - Patient Communication: Do people with spinal cord injury wish to receive written information about their medical condition from the physicians after an outpatient visit or after a readmission in the spinal unit?", *Spinal Cord*, vol. 39, no. 12, pp. 650-653.	**Ref No**	NO.201
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Spinal cord injury**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

This article is based on a survey of people registered with the Southport Regional Spinal Injuries Centre to establish whether they wished to receive written information about their medical condition after a visit to an outpatient or spinal unit.

A questionnaire comprised of 25 questions (requiring 'yes' or 'no' answers) was sent to a total of 128 adults. No person declined to take part in the survey.

Results of the survey

- 106 respondents (83%) wished to receive written information about any changes in their medical condition after an outpatient visit. 8 respondents (6%) did not.

- 104 respondents (81%) wished to receive a copy of the report of intravenous urography after they had attended the spinal unit for a routine annual follow up. 22 respondents (17%) did not.
- 115 respondents (90%) preferred to receive a copy of the MRI scan with interpretation of the findings. 11 respondents (9%) would not.

- 115 respondents (90%) felt that written information about their medical condition would be useful for showing to a GP who may not be acquainted with their medical status. Only 8 respondents (6%) did not.

- 119 respondents (93%) wished to receive written information about any changes in their condition after a readmission to a spinal unit. 6 respondents (5%) did not.

- 122 respondents (95%) did not feel that written information would cause needless anxiety to them. 4 respondents (3%) did.

- 113 respondents (88%) did not feel that written information would cause needless anxiety amongst their relatives or carers. 10 respondents (8%) were worried that it might.

Overall most patients with SCI wished to receive written information about their medical condition after a visit to an outpatient or spinal unit.

Reference	Frieden, L., Smith, L., Wilkinson, W., Redd, L., & Smith, Q. 1998, "Spinal cord injury and managed care: A consumer viewpoint", *Topics in Spinal Cord Injury Rehabilitation*, vol. 3, no. 4, pp. 80-88.	**Ref No**	NO.205

Research methods	Quantitative	Qualitative	Mixed	**Other**
Typology	T1	**T2**	T3	T4
Location of study	UK	**Other (USA)**		
Long Term Condition	**Spinal Cord Injury**			
Confidence Rating	High	Medium	Low	

Key points relating to user's experiences/views of (health or social care) services

Paper discusses impact of 'managed care' on people with SCI. It is a literature review (both research and lay literature) informed by the personal experience of the authors (three have personal experience of managed health care plans). The authors make clear the views expressed are not representative.

The paper is written by academics based in Texas and Arizona USA and therefore much of the discussion relates to the distinctive health care regime of the USA.

Generalisable points include:

- Service organisation and delivery is unlikely to improve unless service users (particularly those with atypical needs) are more actively engaged in shaping services.
- Anecdotal data suggests that attempts to lower costs by restricting access to services may have a disproportionate impact on people who are higher than average users of health care.

Reference	Harker, W. F., Dawson, D. R., Boschen, K. A., & Stuss, D. T. 2002, "A comparison of independent living outcomes following traumatic brain injury and spinal cord injury", *International Journal of Rehabilitation Research*, vol. 25: no. 2, pp. 93-102.	**Ref No**	NO.211
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Traumatic brain injury/spinal cord injury/Spinal Cord Injury**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

A comparison between the groups of independent living outcomes. User experience is NOT a focus of the study. For the record:

Individuals with TBI reported substantially higher levels of independent living in terms of participation/productivity than those with SCI.

The authors hypothesised that this may be because supported employment is offered to the TBI population routinely whereas those with SCI tend not to benefit from this.

They further hypothesise that those with SCI are more segregated due to mobility problems.

Reference	Makepeace, R. W., Barnes, M. P., Semlyen, J. K., & Stevenson, J. 2001, "The establishment of a community multiple sclerosis team", *International Journal of Rehabilitation Research*, vol. 24: no. 2, pp. 137-141.	**Ref No**	NO.214
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

User preferences are presented as part of a paper describing the establishment of a community multiple sclerosis team in Newcastle, England. 116 individuals (those known to the team initially and those referred in the first year) were sent a questionnaire about their opinion of the team; the majority being well satisfied.

Patients were also asked about their perceptions of the important aspects of an MS team. The replies are ranked in order according to particular categories.

1. Accessibility-ability to contact the team as necessary
2. Home visits
3. Continuity of contact with individual team members
4. Emotional support
5. Information service
6. Equipment evaluation and prescription
7. Financial advice

Reference	Scrimgeour, E. M. & Barnes, J. A. 2001, "How do multiple sclerosis patients in Lanarkshire rate health professionals and hospitals?", *Health Bulletin*, vol. 59: no. 3, pp. 155-157.	**Ref No**	NO.215
Research methods	**Quantitative** Qualitative Mixed Other		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other (USA)		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

Survey by Lanarkshire Health Board of members of MS Society to obtain opinion of overall quality of health care provided for them during two previous years in hospital, clinics and at home by doctors, nurses and other health professionals.

119 patients completed the questionnaire, 90 female and 29 male aged 29-60 years. 53% lived in council housing 55 in private housing and only 1 in nursing home – 84% required the use of wheelchair with constantly or occasionally. 82% had significant disabilities for more than 5 years.

Findings include:

- GPs were the most frequently consulted health professionals (75%)
- Followed by hospital specialists (50%) and
- District nurses (41%)
- Speech therapy least utilised service (7%)
- 84.5% patients generally satisfied with quality of hospital care
- Most patients (70%) were satisfied with GPs whereas only 57% approved of hospital specialists
- Many GPs and hospital specialists were deficient in explanations to patients; only 59 and 52% respectively performed satisfactorily.
- District and night nurses well regarded
- Most other health professional rated well but health visitors and social workers received less approval
- Patients frequently complained that they saw a different doctor on every hospital visit and explaining matters to them was deficient in 48.4% of cases and bad in 21% of cases.
- Health professionals should allot more time to ensuring adequate explanations are provided. More graphic explanations were requested.

Reference	Nursing Times 2000, "Patients dissatisfied with continence services... multiple sclerosis", *Nursing Times*, vol. 96, no. 25, pp. 12-13	**Ref No**	NO.217
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

A very short report on patient dissatisfaction with continence services in relation to their condition (MS). The findings were reported at the launch of a new nurse specialist post.

Users identified the following…..

➢ Continence problems are seen as the biggest single barrier to a social life
This in turn leads to

- Relationship problems
- Difficulties on holiday
- Problems in 'going down the pub'

➢ Users are generally unhappy with the advice they receive from GPs and in hospitals. They prefer specialist advice such as are advocated by care-pathways.

Reference	Campion, K. & Cole, A. 1997, "Multiple sclerosis: professional issues", *Nursing Times*, vol. 93, no. 12, pp. 57-62.	**Ref No**	NO.219
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

This piece is really a professional development module for nursing staff. It is interesting for the following:

- It covers the role of the specialist nurse (a much debated theme) which apparently 'improved patients' lives' but it 'had not necessarily reduced the cost to the public purse of caring for MS patients'.
- 'Several surveys of MS patients (unspecified) reveal 'high levels of dissatisfaction with the psychological care given by the healthcare workers and with the provision of services in their own homes, particularly therapy' One study conducted at Manchester Royal Infirmary highlighted absence of information about the disease, the difficulty of getting access to services, poor bladder management and a lack of physiotherapy
- MS Society says much money could be saved if there was concerted action to ensure spending was focused to best effect, e.g. the cost of in-patient admissions to treat MS attacks could be reduced significantly through continuity of care and planned rather than crisis intervention.
- Article argues that as MS services 'fragmented' the role of co-ordinating health worker with specialist knowledge of the disease becomes 'critical' (Specialist nurse). One set up in Lothian regions in 1990, patients, carers and GPs all felt it was helpful and had improved patient' and families' psychological well-being, reduced GP workload and increase patient and doctor knowledge of the management of MS. However, study concluded that although the service seemed to have improved patients lives it had not necessarily reduced cost of providing services to MS patients.

Reference	Williamson, V. K. & Henfrey, D. 1996, "Patient participation in medical audit in primary care", *Social Sciences in Health: International Journal of Research & Practice*, vol. 2, no. 2, pp. 67-79.	**Ref No**	NO.222

Research methods	Quantitative	**Qualitative**	Mixed	Other
Typology	T1	**T2**	T3	T4
Location of study	**UK**	Other		
Long Term Condition	**Epilepsy**			
Confidence Rating	High	Medium	**Low**	

Key points relating to user's experiences/views of (health or social care) services

Main aim of study to test the use and feasibility of patient participation in medical audits through a 'pre-pilot study' of epilepsy care in a south coast fundholding practice. Methodology used 'Critical Incident Technique': an interview method seeking to generate both prompted and unprompted data. Used both face to face and telephone interviews.

Included all patients with a diagnosis of epilepsy aged 16 or over, excluding those with 'mental health problems' . Response rate only 38% (19 patients). Could not improve this figure because of constraints due to 'lack of time and resources'.

Both positive and negative comments are summarised according to 'four sequential stages of care'; initial consultation, diagnosis, initial treatment, and follow-up.

Initial consultation:

- With two exceptions patients thought that their GP's response to their symptoms were sympathetic.
- Further information would have been welcome to some.

Diagnosis:

- A greater proportion of negative experiences are reported at this stage.
- 3 patients reported that they were not formally informed that they had epilepsy.
- Some patients indicated that while they were not told much, they did not ask for further information, as their only concern was the control of their symptoms.
- Some patients wanted more guidance on lifestyles.
- Several patients had anticipated receiving more information at this stage.
- Most patients felt that because the tests were done at hospital, it (rather than the

GP) should be responsible for providing information.

- Reactions were generally positive concerning the clinical interventions carried out.

Initial treatment

- Patients were grateful that symptoms were generally successfully controlled
- Some reported stress due to constant changes of medication and resultant side effects.
- There was a commonly reported lack of information about drug side-effects and lifestyle options; and an ignorance about where to get it.
- Some patients did not want to be more involved in their care.
- Generally patients had expected greater support for the family and more GP involvement.

Follow -up

Contacts with GPs are more likely to be patient-initiated at this stage, with patients more likely to suggest changes in their medication.

- There was a general feeling of confidence in doctors.
- There is still insufficient information about drug treatment and lifestyle.
- Patients stressed the importance of seeing the same doctor.
- There were also 'prompted requests for self help groups'

Conclusion

The paper concludes that lack of information is the most common negative experience reported.

Of particular importance is the need for more information on the effect of epilepsy on pregnancy.

The time of diagnosis is the most problematic for the patients.

Although it was the hospital doctors who were held to be most responsible for diagnosis and initial treatment 'a friendly and understanding GP was greatly valued.

Reference	Bradley, P., Burns, C., Johnson, L., Williams, A., Ray, D., & Burston, L. 1999, "A general practice-based audit of epilepsy care: do primary and secondary care deliver appropriate services for patients?", *Journal of Clinical Governance*, vol. 7, no. 3, pp. 130-135.	**Ref No**	NO.223

Research methods	Quantitative	Qualitative	**Mixed**	Other
Typology	T1	**T2**	T3	T4
Location of study	**UK**	Other		
Long Term Condition	**Epilepsy**			
Confidence Rating	High	**Medium**	Low	

Key points relating to user's experiences/views of (health or social care) services

An attempt to audit patient perceptions and compare these to standards of care. The results were displayed in statistical form and a better picture may have emerged from interviews. As it is, respondents report….

- 10% don't take medication as prescribed
- 33% report a need for more counselling
- 41% report a feeling of stigma attached to the condition
- 84% report general satisfaction with their GP

A short paper with little room for evaluation

Reference	Siderowf, A., Ravina, B., & Glick, H. A. 2002, "Preference-based quality-of-life in patients with Parkinson's disease", *Neurology*, vol. 59: no. 1, pp. 103-108	**Ref No**	NO.224
Research methods	Quantitative Qualitative **Mixed** Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other (USA)**		
Long Term Condition	**Parkinson's Disease**		
Confidence Rating	High **Medium** Low		

Key points relating to user's experiences/views of (health or social care) services

Aim: to "assess quality of life using preference-based scales" with PD patients and to "compare scores with measures of clinical severity and traditional quality of life"

Methods

The study involved 100 participants with a confirmed diagnosis of PD (and without cognitive impairment). The final sample comprised 97 participants who completed all preference-based instruments.

Findings

- The preference-based measures (PBM) tested correlated highly with standard measure of disease severity and health-related quality of life.
- However, there were substantial differences between the scores derived from the PBM. This has important implications for the interpretation of CEA (cost effectiveness analysis).
- PBMs also have a role to play as generic measures of health-related quality of life: they are simple to interpret for professionals and may be particularly appropriate for guiding the use of symptomatic therapies.

Limitations of the study

- Sample was non-random and not necessarily representative. Patients with very mild and the most severe symptoms were underrepresented.
- There was no discussion of patient views on the use of PBMs.

Reference	Kittel, A., Di Marco, A., & Stewart, H. 2002, "Factors influencing the decision to abandon manual wheelchairs for three individuals with a spinal cord injury", *Disability & Rehabilitation*, vol. 24: no. 1/3, pp. 106-114.	**Ref No**	NO.226
Research methods	Quantitative **Qualitative** Mixed Other		
Typology	T1 **T2** T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Spinal Cord Injury**		
Confidence Rating	**High** Medium Low		

Key points relating to user's experiences/views of (health or social care) services

- Evaluation of wheelchair prescription practices for people with SCI in South Australia. Involved follow up of 128 people from time of prescription to one year post issue.
- Results were generally favourable but there was evidence that a small group of people experienced an unfavourable outcome.
- At 12 months post wheelchair issue 8% of the sample were found to have abandoned the wheelchair – half the cases due to death of user.
- Small percentage had returned their wheelchair as they experiences significant functional recovery and no longer required it.
- Of the remaining group high levels of dissatisfaction were reported which ultimately led to the abandonment of the wheelchair before the 12 months had elapsed.

Reference	Osust, T. T. 1999, "Case management: dealing with spinal cord injury", *Topics in Spinal Cord Injury Rehabilitation*, vol. 4, no. 4, pp. 6-9.	**Ref No**	NO.228
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	**T1** T2 T3 T4		
Location of study	UK **Other**		
Long Term Condition	**Spinal cord injury**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services

A user reports on his condition. This is a eulogy to his 'case manager'. The writer details the difficulties experienced in accessing treatment and insurance. The scenario may be typical but is not illuminating here.

Reference	Connections 2000, "Acupuncture and MS - The Patient's view", *Connections*, vol. 36, no. Spring-Summer, pp. 37-38.	**Ref No**	NO.237
Research methods	Quantitative Qualitative Mixed **Other**		
Typology	**T1** T2 T3 T4		
Location of study	**UK** Other		
Long Term Condition	**Multiple Sclerosis**		
Confidence Rating	High Medium **Low**		

Key points relating to user's experiences/views of (health or social care) services
This is the experience of a single individual with no clear generalisability or evidence underpinning it.

Personal experience piece by a woman in her 40s with 'relapsing-remitting' MS detailing her experience of using acupuncture. Acupuncture is used alongside conventional medicine (including steroids) and appears to have a positive impact on certain symptoms (although no impact on others). The author (un-named) makes clear acupuncture is available (and therefore of benefit to her) because she can afford it.

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APPENDIX 3 SEARCH STRATEGY FOR REVIEW

Distribution of references by electronic source

Database	Host	Hits[1]	Selected[2]
AMED	Ovid	64	12
Caredata	Electronic Library for Social Care	20	7
Cinahl	Ovid	102	30
Embase	Ovid	347	63
Medline	Ovid	282	53
SIGLE	Arc	44	4
Sociological Abstracts	Arc	24	6
SSCI	Web of Science	507	40
The Disability Archive UK	Centre for Disability Studies, Leeds[3]	*	5

* The Disability Archive UK was hand searched. The archive contained in excess of 250 documents.

All searches took place in March 2003

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[1] All hits from each search run within the database. This includes duplicates within and between databases

[2] References loaded into reference manager. Duplicates were removed later.

[3] (http://www.leeds.ac.uk/disability-studies/archiveuk/index.html)

Search Strategy for Electronic Bibliographies

Search Terms (multiples)

1.' Persons'	patient, client, service+user, customer
2. 'Focus'	experience*, view*, narrative*, story, stories
3. 'Impairment'	Multiple sclerosis *or* ms, motor+neurone+disease or mnd or amyotrophic+lateral+sclerosis or als or lou+ gehri*, parkinson*, brain+injury, polio, epilepsy, celebral+palsy, spinal+cord+injury, long+term+condition*
4. 'Services'	Health* Clinic* Out-patient* Hospital* Day+Care Social+Services* Social+Work* GP general+practice Community Nurs* occupational+therapy speech+therapy home+care*, social+care, community+care, PCT, primary+care

(nb. The search string 'services' was not used in any of the searches as combinations of the first three strings produced hit numbers that were filterable by hand)

The search terms were modified slightly for the following searches:

Amed
Mapped to subject heading 'patient satisfaction' or 'consumer satisfaction'. Searches were then run by each impairment/condition

Caredata
Mapped to keyword 'user views'. Searches were then run by each impairment/condition. A second search was run for general literature 'Persons' + 'Focus'

Cinahl
Mapped to subject heading 'patient satisfaction' or 'consumer satisfaction' (embaseline 5). Searches were then run by each impairment/condition

Embase

Mapped to subject heading ‘patient satisfaction’ or ‘consumer satisfaction’ (embaseline 5). Searches were then run by each impairment/condition

Medline

Mapped to subject heading ‘patient satisfaction’ or ‘consumer satisfaction’. Searches were then run by each impairment/condition

SIGLE

‘Persons’ + ‘Focus’. Searches were then run by each impairment/condition.

SSCI

‘Persons’ + ‘Focus’. Searches were then run by each impairment/condition

Sociological Abstracts

‘Persons’ + ‘Focus’. Searches were then run by each impairment/condition.

APPENDIX 4 SUMMARY TABLES OF REFERENCES INCLUDED IN THE STUDY

A4.1 Group A Sudden Onset

A.4.1.1Brain Injury

Category	**T1**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		Quant	Qual	Mix/other	Quant	Qual	Mix/other
High							
Medium							
Low							
not rated							
Total no of T1 studies							

Category	**T2**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confid Rating		**Quant**	**Qual**	**Mix/other**	**Quant**	**Qual**	**Mix/other**
High							030, 097
Medium		058	100			061,096	031
Low			032			095	065,062
not rated							
Total number of T2 studies							

A4.1.1 Brain Injury (cont)…

Category	**T3**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		Quant	Qual	Mix/other	Quant	Qual	Mix/other
High							
Medium							
Low							
not rated							
Total number of T3 studies							

Category	**T4**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		Quant	Qual	Mix/other	Quant	Qual	Mix/other
High							
Medium							
Low							
not rated							
Total number of T4 studies							
Total number of studies T1-T4		<no numbers here>					

A4.1.2 Polio

Category	**T1**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		Quant	Qual	Mix/other	Quant	Qual	Mix/other
High							
Medium							
Low							
not rated							
Total no of T1 studies							

Category	**T2**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High			006				
Medium						145, 099	
Low							
not rated							
Total number of T2 studies							

4.1.2 Polio (cont)…

Category	**T3**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							
Medium							
Low							
not rated							
Total number of T3 studies							

Category	**T4**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							
Medium							
Low							
not rated							
Total number of T4 studies							
Total number of studies T1-T4		<no numbers here>					

A4.1.3 Spinal Cord Injury

Category	**T1**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							228
Medium						124	
Low							
not rated							
Total no of T1 studies							

Category	**T2**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High					070, 201	126, 226, 98	067
Medium					066		
Low		051					
not rated							205
Total number of T2 studies							

A4.1.3 Spinal Cord Injury (cont)…

Category	**T3**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High					125	127, 128, 129	
Medium							
Low							
not rated							
Total number of T3 studies							

Category	**T4**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							
Medium							
Low							
not rated							
Total number of T4 studies							
Total number of studies T1-T4		<no numbers here>					

A4.2 Group B Intermittent

A4.2.1 Epilepsy

Category	**T1**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							
Medium							
Low							
not rated							
Total no of T1 studies							

Category	**T2**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High		103, 110	101, 054	120, 048, 111	049, 109, 171		117, 160
Medium		113, 115	106	102,223	050, 119, 162		
Low		105	104, 222				118
not rated				107,108, 112			
Total number of T2 studies							

A4.2.1 Epilepsy (cont)….

Category	**T3**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High		053				056	
Medium							
Low							
not rated							
Total number of T3 studies							

Category	**T4**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							
Medium						92	
Low							
not rated							
Total number of T4 studies							
Total number of studies T1-T4		<no numbers here>					

A4.3 Group C

A4.3.1.Cerebral Palsy

Category	**T1**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High			016				
Medium							
Low		140					
not rated							
Total no of T1 studies							

Category	**T2**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High			147		123	98	
Medium				148		122	
Low							
not rated				017			
Total number of T2 studies							

A4.3.1 Cerebral Palsy (cont)…

Category	**T3**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							121
Medium							
Low							
not rated							
Total number of T3 studies							

Category	**T4**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							
Medium							
Low							
not rated							
Total number of T4 studies							
Total number of studies T1-T4		<no numbers here>					

A4.3.2 Motor Neurone Disease

Category	**T1**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High				068, 074, 078			
Medium							
Low		052, 076, 077, 057		059			
not rated							
Total no of T1 studies							

Category	**T2**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High				063, 047, 154			
Medium		080		060			
Low							
not rated		152					
Total number of T2 studies							

A4.3.2 Motor Neurone Disease (cont)…

Category	**T3**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							
Medium							
Low							
not rated							
Total number of T3 studies							

Category	**T4**	NO. ref numbers (UK)			NO. ref numbers (other locations)		
Confidence Rating:		Quant	Qual	Mix/other	Quant	Qual	Mix/other
High							
Medium							
Low							
not rated							
Total number of T4 studies							
Total number of studies T1-T4		<no numbers here>					

A4.3.3 Multiple Sclerosis

Category	**T1**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High		215			184		
Medium			007				
Low				237			
not rated				132			
Total no of T1 studies							

Category	**T2**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High		084, 087, 185		219	040, 082, 188, 190	014, 098	042, 183
Medium			131	145, 214			081
Low			013	085, 217			
not rated						083, 182	
Total number of T2 studies							

A4.3.3 Multiple Sclerosis (cont)…

Category	**T3**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High		046	186				
Medium							
Low							
not rated							
Total number of T3 studies							

Category	**T4**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							
Medium							
Low							
not rated							
Total number of T4 studies							
Total number of studies T1-T4		<no numbers here>					

A4.3.4 Parkinson’s Disease

Category	**T1**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							
Medium		143					
Low				192			
not rated			089				
Total no of T1 studies							

Category	**T2**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High		073, 090		136, 196, 134			075
Medium		114		008, 193	130		197, 224
Low							
not rated			133				
Total number of T2 studies							

A4.3.4. Parkinson’s Disease (cont)…

Category	**T3**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							
Medium							
Low							
not rated							
Total number of T3 studies							

Category	**T4**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							
Medium						NO.92	
Low							
not rated							
Total number of T4 studies							
Total number of studies T1-T4		<no numbers here>					

A4.4 General

Category	**T1**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High							
Medium							
Low							
not rated							
Total no of T1 studies							

Category	**T2**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating		*Quant*	*Qual*	*Mix/other*	*Quant*	*Qual*	*Mix/other*
High		015, 004		019, 138, 141	039, 211	098	038
Medium				020	151		002, 002
Low						044,009	
not rated							
Total number of T2 studies							

A4.4General (Cont)….

Category	**T3**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		Quant	Qual	Mix/other	Quant	Qual	Mix/other
High							
Medium							
Low							
not rated							
Total number of T3 studies							

Category	**T4**	**NO. ref numbers (UK)**			**NO. ref numbers (other locations)**		
Confidence Rating:		Quant	Qual	Mix/other	Quant	Qual	Mix/other
High			003, 023, 028	005, 195			
Medium			021	034			
Low				024			194
not rated							159
Total number of T4 studies							
Total number of studies T1-T4		<no numbers here>					

APPENDIX 5 REPORT

Notes from NO. Workshop Meeting held on Friday 21st March 2003 at SPRU

Present:	Sonali Shah; Alex McClimens; Jennifer Harris; Hannah Morgan; Stephen Piper; Carol Thomas; Hazel Qureshi NB the views of Colin Barnes and Geoff Mercer were elicited at an earlier meeting are included in this report.
In attendance:	Gill Gibbeson

The meeting was opened by Jennifer Harris who welcomed everyone and asked each person present to introduce themselves. Jennifer explained that the aim of the workshop was to look at the studies reviewed on the individual impairment groups and discuss the key findings from the proformas. The aim then was to look at the general literature review group and discuss any issues arising from these findings.

KEY THEMES:

Multiple Sclerosis

Depending on severity of condition the perception of services used were different. The perception of professionals who were helpful also was dependent on the severity of the condition. A large number of users tended to go into hospital with specialist clinics for MS. They found specialist nurses particularly helpful.

Users did not want to be surrounded by professionals, they wanted a say in who they saw – it was dependent on the severity of their condition at the time but they wanted some say in how the clinic was organised.

Users had gained expertise themselves with regard to their condition. They had found a helpline run by a drug company had been very useful.

Users saw pain as a significant problem but found this was not recognised as a significant issue amongst professionals. Users wanted pain management advice at the clinics.

One study had focused on social care provided by Social Services. This found that there was a need for improved communication between providers of social care and people with MS. It found that those people with more hidden symptoms were not recognised as needing help by Social Services. Only a very small proportion had a key worker and only a small proportion were ever offered certain kinds of assistance and certain kinds of services. Main recommendation being that a key worker is identified so that people with MS can be more clearly linked into the system to obtain services.

A comment was made that focusing on the condition was not as helpful as perhaps focusing on the type of impairment because of the vast difference in symptoms. He also felt that it was not particularly helpful to focus on a service for people with MS, for example, because their experiences and needs were so diverse but that it would be more helpful to focus on something such as visual impairment which is of more significance to them than the general diagnosis of MS.

Users did want professional expertise, such as drugs available and side effects, treatment etc., if they were ill, but they were also concerned with things which were not to do with the condition such as a visible or invisible impairment or communication difficulties which were just as important and which cut across the spectrum of conditions.

Epilepsy

Doctors' interpersonal skills seemed to affect the level of satisfaction of the service felt by users: the amount of time doctors gave to the patient affected their perception of the service they received.

A comment was made about a paper from South Africa – it's findings did not relate well to the UK as the study covered patients in severe poverty who experienced chaotic lifestyles due to their poverty. The main findings of the study brought out the difficulties experienced if the patients did not stick to a strict drug regime. The patients' disability grants were affected if they did not comply.

It was commented that two studies which linked looking at the efficacy of having specialist nurses available in a primary care setting. A specialist nurse was highly valued by users. Users felt that doctors did not have enough time to spend discussing the details of epilepsy with patients whereas nurses had more time, were empathetic, compassionate, understanding and seemed knowledgeable about epilepsy and were able to give a lot of information which was of practical use to users. There was a consensus that other studies had similar findings.

It had been found that users felt that hospital doctors knew more about epilepsy but that there had been a recommendation that hospital care should be turned into epilepsy centres where specialist nurses would have a role in delivering information about epilepsy and bringing together epilepsy patients. In another paper the primary finding was a deficit of information provision on epilepsy and the drugs needed, particularly for women who were not told by their GP that they could not have certain drugs if they were pregnant.

It was noted that users were unhappy about the lack of counselling available regarding their condition. It was noted that users who had attended specialist centres for epilepsy both in the UK and Sweden had felt their situation had improved in the 6 months they had been attending the centres.

A study looking at patient education which had put forward a strong case for the importance of patient education in the nature of the condition and the other aspects of living with epilepsy, for example it should address issues of discrimination, stigma, as well as the more medical/clinical aspects of controlling seizures, the nature of drug treatments etc. If there is education on all these fronts it makes a tremendous difference to the quality of life, to the ability of users to challenge discrimination and to improve users confidence and self esteem. One study that users who had formed self help groups were contacting other self help groups and educating themselves. People needed to have a sense of control over their lives, their destinies and their condition and critical to this was access to expertise, information, education. The underlying need was to be able to gather together all the information necessary for users to feel in control of their lives.

A point was made that what came across in the studies was listening to the person with the condition was important because they were the experts. It was agreed that the studies showed this was what people wanted.

Spinal Cord Injury

A study in the USA about the psychosocial aspects of spinal cord injury – being more than a head – becoming a whole person again, found that users felt that the influence of nurses were central to achieving this.

Another study which had grouped various conditions together including stroke patients, traumatic brain injury and spinal cord injury found that inadequate personal assistance, poor nutrition, poor hygiene meant a longer hospital stay.

Motor Neurone Disease

Users felt there was a lack of knowledge by doctors and the general public regarding MND. They felt abandoned. Prevalence of MND so low that the health service did not have much knowledge of the condition. There was a depressing account of failure of the medical profession. Concern over delays of referrals for the supply of equipment and adaptations had been expressed. The system did not go fast enough for people with a progressive illness. A study based in Scotland found that needs were met much quicker if identifiable carers were involved.

Brain Injury

Networking with families in a similar situation had resulted in coping strategies being passed on. Patients whose symptoms did not get an immediate diagnosis found they had a struggle to get a diagnosis and felt marginalised because professionals and families would not take them seriously. Users who were not in a fit state to negotiate found this a barrier to access of services. They valued help with advocacy, dealing with services and filling in forms etc.

A study of patients in a permanent vegetative state found that 4 emerged from this state so there was a mis-diagnosis although they were still severely disabled. It was felt that there were still skills missing - assessment should be continual because some people do recover.

Cerebral Palsy

A study in Australia found that users felt that when they had to go into hospital the staff did not have the skills and knowledge for caring for the needs of patients with CP. A lot needs to be done in nurse education. A general study which included women with CP found that they felt their GP was the passport to employment, education and service provision.

Polio

One study which covered polio and the ageing process gave a sense that the condition was not well understood by professionals because the condition is not known now. They felt they were not well supported. Another study looked at the effects of polio focused on childhood experiences and did not cover current experiences as service users except to find that there was a general level of satisfaction with current services.

Most studies covered older people which fell outside of the criteria for the research.

Parkinson’s Disease

A document for health professionals regarding treatment needed for people with Parkinson’s Disease highlighted the need for respect for patients’ opinions.

A study in the USA looked at a management programme and those taking part found that they felt healthier in themselves when treated with this programme but doctors did not find the programme helpful.

A study by the Parkinson’s Disease Society which looked at standards of care when patients were admitted to hospital and their experience on the wards found that only

52% received their medication at the correct time. Timing of medication was critical for patients to manage their condition properly. Only 27% of staff understood the on/off nature of the disease. Patients were not able to easily access a PDS nurse specialist. The study found that patients' communication needs, mobility needs, special dietary requirements were not met so the recommendation was that patients should be given a more active role in being able to manage their condition while in hospital particularly with regard to medication.

Another study found that Parkinson's Disease patients who had undergone a general anaesthetic found that they were worse post operatively because of the effects on their medication – 94% were very dis-satisfied.

A questionnaire survey on access to therapy services such as physiotherapist, occupational therapist or speech therapist found that half of those surveyed had accessed therapy services and the majority felt they could get access to services from their GP if needed.

Another survey found that a lot of people were not aware of services, particularly respite care services. A second study of people who did receive respite care services were not happy with respite care. Both studies indicated that users complained about how GPs and specialists handled communication, both the physical aspect and the administrative side. They reported the feeling of being abandoned between consultations. Users identified some physical symptoms that they were not sure if they required intervention or not. Users reported they could have done with more advice on medication and lifestyle issues. A lot of patients under-reported the symptoms of depression. Help was often only received in times of crisis. Users would prefer the self-referral option rather than waiting for the consultant to see them. Users did not see services as responsive to their needs.

A letter to the BMJ about the right of people with PDS to participate in drug trials had been reviewed. The person writing had taken part in a drugs trial and the drug was subsequently withdrawn and he was now paying for the drug himself. He felt that the drug had made a huge difference to his quality of life.

General

Several studies talked of including user involvement but very little had been done to move this forward. There was one study based in Liverpool on accessible health information which had been very successful.

Point about doctors not being well informed, people being worried about the ageing process as well as the disease process.

One piece of research regarding users with learning difficulties suggested that some service users might not be so forthcoming with issues because they were reliant on service providers.

It was noted that there was little about user involvement in the pieces of research and little on social care. The issues raised by the research pieces were very diverse, not just about access, finance, transport issues. There is not a recognition of what is important for people – getting on with their daily lives.

Individual case studies were found to be more revealing.

Key messages and cross cutting themes

Medication
Information
Consulting patients
Professional/patient relationship
Health professionals a barrier to normal life
MS & Epilepsy specialist nurses
Quality of Life > Health
Abandoned by health professionals
Impairment categories
Timeliness of service (e.g. need to be prompt for certain categories)
Critical support for emotional well-being
Crises
Explanations → e.g. drugs – side effects
Continuity of Care