Executive Summary

‘User experiences of health and social care services’

The Department of Health commissioned a brief scoping study be carried out in order to amass evidence on user experiences of health and social care services. The study covered people with long-term conditions of working age only (18-65). The study was directed towards exploration of following: Group A: ‘Sudden Onset’: Brain Injury, Polio Spinal cord Injury; Group B: ‘Intermittent’: Epilepsy: Group C: ‘Progressive’: Cerebral Palsy Motor Neurone Disease, Multiple Sclerosis and Parkinson’s Disease. The study aimed to identify literature that contained evidence on ‘user experience of health and /or social care services’ in the target groups. Highly rated studies are marked * throughout this summary.

Findings from Group A: ‘Sudden onset’
Brain Injury

- *Neurosurgeons sometimes over-state the degree of recovery and normal functioning in patients when comparison is made with patient and family members’ own evaluations.

- *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 can lead to networking opportunities, that these are mutually beneficial and that they have changed their behaviour based on information received.

- *TBI patients report substantially higher levels of independent living in terms of participation and productivity than those with SCI. This may be because supported employment is offered routinely to the TBI population whereas those with SCI tend not to benefit.

- People with brain injury 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.

- There is a current paucity of service provision for this group of patients.

- Full and accurate assessment of needs of person and any carers.

- Provision of information, support and counselling for user, carers and family members soon after injury

- Post-acute rehabilitation services are required

- A comprehensive range of support services in the community and a range of residential service options are required.

- The 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.

Polio

- *Most users with polio are now older people (many post retirement). Many experienced very poor treatment from health and social care services as children, some appear to be psychologically damaged by these experiences, memories of which sometimes return.

- *Ageing with polio comprises two sets of experience – impairment effects may compound each other. Users found the physical consequences of impairment difficult to cope with – ageing made these worse.

- *As polio has been almost completely eradicated, users feel forgotten by services – especially from service planning and provision.

- *There is a general lack of professional understanding about polio – particularly from the medical profession. Post polio syndrome (PPS) was not well understood by doctors – some users are made to feel that they are hypochondriacs.

- *There is a general lack of specialist clinics and problems with travelling to large hospital sites and lack of routine check ups for users.

Spinal Cord Injury

- *Users report nurses post injury assist in getting ‘back together as a person’

- *Adequate personal assistance is related to the ability to maintain good physical and mental health

- *Inadequate personal assistance leads to extended hospital stays, threats to safety, poor nutrition and poor personal hygiene. Individuals who rely on family alone found they suffer from burnout, family role change and economic strain.

- *Users experience problems obtaining sufficient personal assistance (PA). Lack of PA also creates difficulties in using and maintaining adaptive equipment.

- *Patients experience discomfort during group presentations on sensitive topics. There is generally insufficient information, and a direct, open style is preferred for giving information.

- *Patients would find written information about their medical condition useful to show to their GP who may not be acquainted with their medical status

- *Users need more information on fertility and parenthood

- *Users with the best health combine assistance by relatives with that given by unrelated persons

- *Pain management avenues are not always thoroughly explored

- *Cognitive Behaviour Therapy helps patients acquire new skills in controlling anxiety, controlling depressed mood, living as a person with sexual needs, coping with future problems, improving communication and assertion skills. It is recommended that CBT should be a standard component of rehabilitation for patients.

- *Service organisation and delivery is unlikely to improve unless service users (particularly those with atypical needs) are more actively engaged in shaping services

Findings from Group B: ‘Intermittent’

Epilepsy

- *Users want more information to be given on their condition and its management. Receptiveness to information is key to understanding.

- *Specialist nurses improve communication between patients and healthcare providers.

- *Epilepsy surgery is frequently effective in weaning patients off anti-epileptic drugs

- *Users want to work, drive, have independence, socialise and have freedom from drugs

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

- *The majority of users rate services highly

- *Some studies note that the doctor's interpersonal style is influential in affecting patient satisfaction overall. This includes being approachable and accessible

- *Patient education should be seen as central to health professionals involved in epilepsy care

- *The negative impact on other family members is an area highlighted as needing more research

- Users want to see more effective communication from health care service providers

- Users want more information on side effects of medication and antiepileptic drug use in pregnancy

- There is a particular call for medical and health care staff to spend more time explaining diagnoses to patients

- Users voice support for specialist nurse run provision of services. These services appear to improve communication deficits experienced elsewhere in the system

Findings from Group C: 'Progressive'

Cerebral Palsy

- *Users expressed a wish to have access to emotional support, counselling and/or psychotherapy. The few who had experienced psychotherapy had found this helpful. The emotional needs of their parents and siblings were often not recognised.

- *Experiences of the education training and employment systems varied. There were some reports of dissatisfaction with schools and discrimination in employment.

- *Professionals were insufficiently familiar with their particular condition. Most users were quite satisfied with their regular GP. Most cases of insensitive or unsatisfactory medical treatment relate to experiences in hospital.

- *Aging brings an increase in physical problems but few users visit their GP for regular checks and the majority had not seen a consultant or physiotherapist for at least five years. Users express anxiety about the future, particularly in relation to further physical deterioration.

- *Time taken to obtain home equipment and adaptations is often too long. Social work support is viewed favourably in around 50% of cases. Occupational Therapy (OT) received was satisfactory in around 60% of cases.

- *There are endemic tensions and creativity in multi-disciplinary working - these can have positive or negative effects on service users. There is a danger that the ‘culture of professionalism’ negates user views and ‘listening to users’ involves moving from reactive crises management to proactive crises prevention services.

- *If a concept of ‘total care (social, emotional and psychological needs) is adopted there are ‘glaring deficiencies’ such as skilled counsellors, lack of support at crisis points and lack of coherence between professionals especially when creating a bridge between core medical needs and wider social needs.

- *Hospital staff have limited knowledge and skills in caring for people with CP. Basic care needs are not being adequately addressed during hospitalisation. Changes in nursing assessment, continuing education and discharge planning are recommended.

- *Cerebral palsy related pain is under-treated in the adult population with CP. Despite the reported helpfulness of the pain interventions, however, most are only being used by a small amount of patients.

Motor Neurone Disease

- *Users are concerned about the lack of knowledge and understanding of MND displayed by many medical professionals and by the general public. They also experience a lack of information about the diagnosis. This view is held by many patients within Motor Neurone Disease Association (MNDA) groups

- *Health professionals require advice and information from people with expertise such as MNDA advisers

- *Many patients are referred to non-neurological specialists, which they feel delays the diagnosis of MND.

- *Speedy diagnosis is essential for MND patients. Education of medical and health professionals to identify early symptoms of MND would enable patients to make the most of remaining time.

- *At diagnosis, there is a great need for sensitive handling (by the neurologist and other health professionals). Patients should have a relative or friend present when diagnosis is given

- *MNDA should continue influencing the education of GPs and other health and social care professionals about the early symptoms of MND and encourage early referral to neurologists, encouraging the latter to ensure that patients are not told the diagnosis alone, that professional counselling is available and influencing service providers to urgently supply grants for adaptations and equipment (especially the supply of wheelchairs)

- *Since MND is progressive, degenerative and rapid, patients require fast tracking for a number of aids and adaptations. Generally speaking, the ordering systems for equipment appear to fail people as the disease progresses faster than the items can be delivered.

- *Patients can deteriorate quickly, so their needs change quickly, while services are only able to react slowly

- * Continuity of care personnel; fast track referrals to paramedical personnel; equipment availability and timely delivery; having named key workers and palliative symptom management are important to users

Multiple Sclerosis

- *Many GPs and hospital specialists were deficient in explanations to patients. District and night nurses were well regarded. Health visitors and social workers receive less approval.

- *Patients complain that they see a different doctor on every hospital visit and explaining matters to them was deficient in half of cases. Health professionals should allot more time to ensuring adequate explanations are provided. More graphic explanations of medical information are requested.

- *The MS Society believe much money could be saved if there was concerted action to ensure spending was focused to best effect, for example, the cost of in-patient admissions to treat MS attacks could be reduced significantly through continuity of care rather than crisis intervention. As MS services are ‘fragmented’, the role of co-ordinating health worker with specialist knowledge of the disease is ‘critical’.

- *Patients who under thalamotomy for the intention tremor report mixed views on its success. Surgery reduces tremor in some patients but does not always translate into quality of life improvements.

- *Specialist nurses improve patients’ lives but do not necessarily reduce the ‘cost to the public purse of caring for MS patients’.

- *Users are more likely to experience pain, the longer they have the disease.

- *A considerable proportion of users have problems with standard issue wheelchairs, including technical, propulsion and general discomfort issues.

- * Prolonging home care and postponing early institutionalisation is a high priority

- *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.

- *Users wish to gain control over uncertainty, dependency and physical and emotional decline.

- In community MS teams, accessibility to the team is key and users rate highly home visits, continuity of contact with individual team members, emotional support, information services and equipment and financial advice.

- Patients benefit from having access to an MS specialist neurologist

- In terms of injection anxiety, self-efficacy expectations were significantly related to adherence to drug regimes.

Parkinson's Disease

- *The diagnosis-giving process is often not handled well by GPs or specialists. On-going communication with professionals is similarly poor. Many users do not know about other available services such as respite care and that under-reporting of symptoms (especially depression) is common.

- *Users report high dissatisfaction with peri-operative management with 94 per cent complaining of confusion or worsening of their condition post-operatively and that medical administration problems are common.

- * Mobility issues; falls; work-related problems; problems in household management, social isolation and limited leisure; difficulty taking holidays, financial problems, premature retirement from work leading to reduced income; more health-related costs, depression, loss of control, speech difficulties and cognitive impairment are all important to users

- * Provision of PD nurse specialist (PDNS) compared with the consultant cannot be recommended solely on cost-effectiveness grounds because of similar outcomes but increased costs with PDNS providing additional care. However, patient and carers feel PDNS make particular contributions to their care.

- 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 appropriate services provided

- Patients 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 of a particular treatment and its adverse effects.

- Healthcare professionals and policy makers need to understand that their own perceptions of health may differ from those of their patients.

- Users want to be listened to by professionals and want their experience to be valued and respected.

- Users should have the right to make informed choices over whether to take certain drugs for PD.

- Users need more advice on medical and lifestyle issues. They feel they have a lower quality of life due to lack of key services.

- As a group, users are well able to say what a good service should look like.

Findings from the ‘General’ literature:

- *Disabled women’s relationships with their GPs are often problematic with the result that they are viewed as disabled first and women second. GP prejudice and low expectations of disabled women can lead to women not being adequately supported in making informed decisions and choices particularly around contraception and pregnancy.

- *Communication difficulties are sometimes linked to impairment/condition but greater difficulty is caused by ‘speaking’ people not having the experience, time or commitment to try to understand and be inclusive.

- *Disabled people from minority ethnic communities (south Asian and afro-Caribbean) experience cultural insensitivity across a range of services and physical barriers that prevent many people accessing health and social care facilities.

- * The provision of accessible information within the NHS is important, as is acting on user views

- *It is important for social workers, to listen to clients’ stories/narratives. This method is seen as much more user-centred and provides space for service users to explore the ways their conditions impact of their lives and to explore their priorities

- *Health professionals remain uncertain about which consumers to involve, which methods of participation to select and how to adequately support user involvement. Genuine consumerism means hearing voices that speak ‘for the perspectives, ideas, interests and values of patients, users and carers *as they define them*’.

- Disabled people can and want to take control of the management of their impairment/conditions. However, disempowering professional attitudes and practice can limit this

- Inclusive practice is vital to ensure equitable access to services, most notably in relation to physical and communicative access and cultural and gender sensitivity.

- Service user consultation and involvement in research must have tangible results and particular attention should be paid to ensuring findings are suitably disseminated.

Project Director: **Dr. Jennifer Harris, Senior Research Fellow, Social Policy Research Unit, University of York, York, YO10, 5DD.**

Project Team:
Stephen Piper
Hannah Morgan

Expert Panel:
Alex McClimens
Carol Thomas
Sonali Shah
Geoff Mercer
Colin Barnes
Hilary Arksey
Hazel Qureshi