



**NEUROLOGICAL INFORMATION AND ACCESS
PARTNERSHIP (NIAP)**

Professional Survey Report

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**Improving access to rehabilitation, information and advice in
Nottingham City and Nottinghamshire County**

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Acknowledgements:

We would like to thank the participants who gave up their time to complete the survey and speak to the researcher. We would like to thank the NIAP steering committee and we acknowledge financial support from the Department of Health Section 64 funding stream. A full list of grant holders and steering committee members can be seen at Appendix 1

A copy of the survey used can be obtained by contacting the author

Executive Summary

Aim

The aim of the NIAP project was to identify gaps in current neurological service provision and make recommendations for improvements and new ways of working in Nottingham City and Nottinghamshire County.

Method

A short on-line questionnaire was designed following discussions with professionals from statutory health services, voluntary services and social care services. The survey had sixteen questions about access to services, barriers to services and ideas for improvements.

Findings

The online survey was completed by 90 members of health and social care staff. A number of 1:1 interviews with individuals and small group discussions were held by the researcher. The main findings were that staff knew that services existed but didn't always know if their service users were eligible or how to access the service. Some felt they were using a 'scattergun approach' where they referred their patients to services with the hope that something would fit their needs. Most had referred their patients to statutory and voluntary services and felt these services had an essential role to play in support and treatment. Many respondents felt that a specialist referral point and single database of services for neurological conditions would be excellent idea but were concerned that the service advisors would need specialist training and on-going support to be able to provide an excellent facility.

Conclusion

Professionals working with people who have neurological conditions are faced with a plethora of services which they can refer their service users to. A specialist referral point for services and information would seem to be the first step to providing quicker and targeted interventions.

Recommendations

- Extend knowledge of neurological service provision across staff in all sectors, including GP's
- Training in neurological conditions and related symptoms for health and social care staff
- Seek funding for a neurological information and advice service in Nottingham City
- Implement and promote a specialist referral point for neurological service access
- Provide neurological training for service advisors who will provide the specialist referral point
- Ensure on-going financial and organisational support for new policies
- Support the integration of data base systems across health and social care

Background

Research studies have highlighted the fragmented and disorganised health and social care services for people with neurological conditions. A project that mapped all specialist neurological rehabilitation services in the UK (Gladman et al 2008) found that services tend to be focused on diagnosis and early management with limited services for long term conditions such as Multiple Sclerosis. In 2005 The National Service Framework for Long Term Neurological Conditions (NSF- LTC) (Department of Health 2005) recommended integrated action and joint working between all agencies with the aim of providing a patient centred, coordinated and seamless service.

In 2009 the Neurological Information and Access Partnership (NIAP) was launched with financial support from Department of Health Section 64 funding stream to address the local fragmented health and social care service and to implement the recommendations of the NSF-LTC. Working across the Nottingham City and Nottinghamshire County, the project was administered by Parkinson's Disease Society. It consisted of a large partnership of voluntary and statutory organisations including Nottingham City Council, Nottinghamshire County Council, NHS Nottingham City, NHS Nottingham City – Nottingham CitiHealth, NHS Nottinghamshire County, Nottingham University Hospitals, University of Nottingham and neurological charities such as Multiple Sclerosis Society, Headway and Motor Neurone Disease Association. One of the important parts of this project is that the NIAP is managed by the Parkinson's Disease Society; the project manager is employed by the Parkinson's Disease Society and is therefore an independent researcher not reliant on the NHS or Social care for funding.

The aim of the NIAP was to develop an environment where seamless and appropriate access to specialist rehabilitation services, information and advice could be provided in a timely fashion for people with neurological conditions. By providing this environment it is hoped that fragmented services can be brought together, the duplication of resources can be reduced, health and social care services can be enhanced and the quality of life for people with neurological conditions can be improved. To achieve this aim a number of smaller projects were planned. One of the first was to understand how service users access information and any barriers to advice and information. The second was to understand from professionals in the health, social care and voluntary sectors how they access information and how they help service users get the correct advice. This is a report of the professional survey. A copy of the service user survey used can be obtained by contacting the author or by going to www.parkinsons.org.uk/neurosurvey

Method

The area under scrutiny in this project covers a large geographical area. Nottingham and Nottinghamshire are unitary authorities with clearly defined boundaries creating a division of services across Nottingham City and Nottinghamshire County. There are a number of hospitals based across the region treating patients from both authorities as well as countryside.

Between May and August 2009, the researcher met with health and social staff and service users accessing neurological services to compile a list of areas that were important to those working and living with neurological conditions. These topic areas were distilled down into a number of questions about how health and social care

staff, service users, family, friends and carers access health and social care services and how they had acquired meaningful information and advice on support services. The questions were also derived from the proposal in the original project bid as well as the NSF- LTC.

A survey, using these questions was designed with spaces for written comments as well as yes/no questions. The survey was piloted with the NIAP steering group and health and social care staff. The aim of the survey was to assess how staff from primary, secondary and acute services access service provision, to identify gaps and obstacles. At the same time as gathering data the population were asked to comment on the concept of a specialist referral point to information and referral to services that staff and service users could use. A scoping exercise of health and social care teams across the region was established to ensure that a diverse range of staff were targeted these included: Linden Lodge Rehabilitation Unit, Chronic Obstructive Pulmonary Disease teams, Early Supported Discharge Team, Community Stroke Team, Traumatic Brain Injury Unit, Community Matrons, Independent Living Teams, Community Heart Nurses, Intermediate Care Team, Speech and Language Therapists, Specialist Nurses, Chatsworth Rehabilitation Unit, Nottingham University Hospitals Rehabilitation services, Neurological Physiotherapy out patients clinic, Falls teams and Musculoskeletal Teams. The surveys were promoted on local and regional web and intranet sites as well as in publications and newsletters. Face to face interviews were completed by the researcher to gain a deeper insight into issues faced.

In particular the interviews were keen to establish:

- The span of neurological conditions prevalent across the region
- If staff are aware of the full range of services available across sectors
- If staff are aware of the correct referral pathways into provision
- What are the main obstacles around service access
- How service users/carers are signposted to voluntary/public services
- Any issues relating to data base systems
- To present the concept of a specialist referral point for information

The internet survey was collated by 'Survey Monkey'. The field notes and hand written comments from the survey were analysed using a thematic approach, where comments and quotes made by different people but on the same theme were grouped together. As more interviews were completed the researcher added the comments and quotes to the existing themes if appropriate or started a new theme. Once all interviews were completed the themes were reviewed for completeness and checked by a second researcher. The quotes have been anonymised and are printed in italics.

The University of Nottingham helped to complete the analysis.

Findings

Participant Characteristics

Although a wide range of health and social care staff were targeted a relatively small number of responses were received to the on-line survey totalling 90 in all (68 from staff based in Nottingham City and 22 from Nottinghamshire County. However they were received from a wide range of professions (24 Occupational Therapists, 13 Physiotherapists, 6 Speech and Language Therapists, 1 Medical Consultant, 3 Social workers and a number of rehabilitation support workers and team managers). Not all respondents completed all questions. When asked in the face to face interviews why people had not completed the survey they said it was mostly due to a lack of time,

some thought it not appropriate as they do not see neurological patients as the primary referral reason and one team completed the survey as a team.

Prevalence of neurological conditions

A wide range of neurological conditions were reported as being prevalent across the region. These included deteriorating diseases such as Parkinson's Disease, Motor Neurone Disease, Multiple Sclerosis, Huntington's disease, Charcot Marie Tooth Syndrome and Acute Ataxia. Other conditions included stroke, traumatic and acute brain injury, Dementia, Guillian Barrie Syndrome, Muscular Dystrophy and Cerebral Palsy; in total 46 neurological conditions were identified. Referrals to professional rehabilitation services were received from a range of different sources. GP's provided the greatest number of referrals for PD (65%) and MS (66%). Medical Consultants made the largest number of referrals for PSP (Progressive Supranuclear Palsy) and hospital ward staff made the largest number of referrals for stroke (70%).

Services and pathways

Two thirds of the staff completing the on-line survey stated that they were aware of the correct pathway for a service user to take when they needed a particular type of treatment. See Figure 1. More of the sample knew what each service could offer to patients. See figure 2. There were some responders that knew the service well but did not know how to access the service. Out of 88 respondents 73 (83.0%) said that they were aware of the full range of hospital services but 64 of those (72.7%) were less sure in relation to the correct pathway.

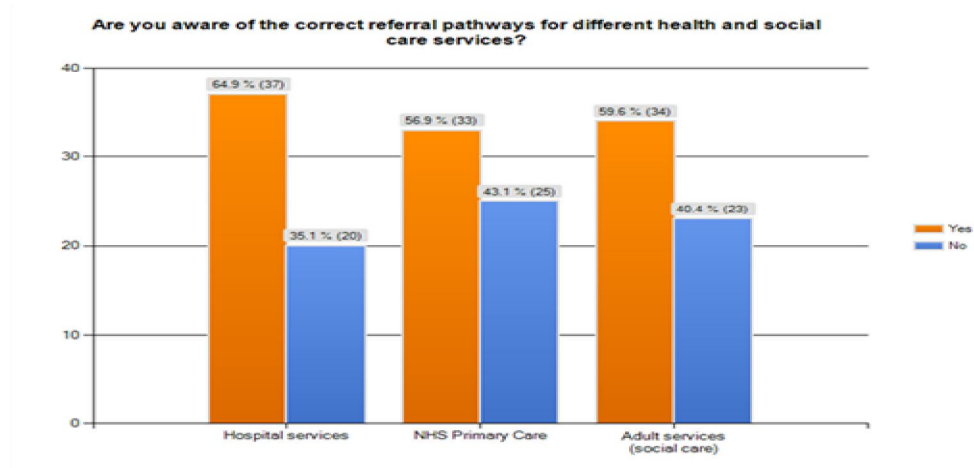


Figure 2: What services can offer to patients

These results were somewhat contradicted during face to face interviews which indicated a lack of knowledge in relation to services as a whole, regardless of whether they were in the same organisation or not. Most participants found it difficult to keep up-to-date with the different types of service across different sectors and stated that they mostly used services they already knew.

“Teams change so much it sometimes feels that the system is deliberately made difficult, it sometimes seems there are more exclusions than inclusions”

When asked how clearer access to information about other services could improve patient care; the majority of respondents felt that waiting times for community services would be reduced, there would be a reduction in hospital admissions and earlier hospital discharges. The interviews confirmed that professionals would like access to, and information about, services that patients are already receiving.

“Clearer access to services would lead to reduced waiting times and ensure a more evenly distribution of referrals. Sometimes it is clear an assessment has been done but I have to telephone the service to get details which takes time”

Some respondents constructively pointed out that clearer pathways are irrelevant if there are not enough services to refer into and this has to be addressed by senior management and built into future service planning. Concerns were also raised over the inequalities to patients across Nottingham City and County caused by unequal service provision often dependent on postcode. NIAP has the advantage of working jointly across City and County with representatives sitting around the table from all sectors both geographically and organisationally and the project will continue to identify gaps and work towards improved service access and provision engaging with projects such as the Community Neurology Service in Nottingham City and the Managed Clinical Network in the County.

“Patients get discharged too early and then end up back in hospital due to lack of resources and support which is not consistent with social aspects such as adequate equipment”

Referral to service provision

When asked what the obstacles to making a referral to health and social care, the main issue indicated was a lack of time (80%). However we are not sure if this means the professionals do not have time to make the referral or if they do not have time to find the appropriate service. Another major obstacle was multiple referral points, making it difficult to be certain that a service user had been referred appropriately. Participants reported that they would refer service users to more services if the process was easy, quick and relevant. Some participants referred their service users to more than one service in the hope that the correct pathway was reached.

“if we could refer to the correct team immediately and patients got seen quicker then we could get help out there before they get to crisis situation and have no alternative but be admitted to hospital”

Thirty nine out of 62 respondents, preferred to use the telephone to make a referral to a different service, many with a written following letter. Staff felt that a personal discussion could save time in the long run helping them to pass over relevant

information and get an assurance that their referral would be dealt with by the correct person. Figure 3 shows how the participants made referrals.

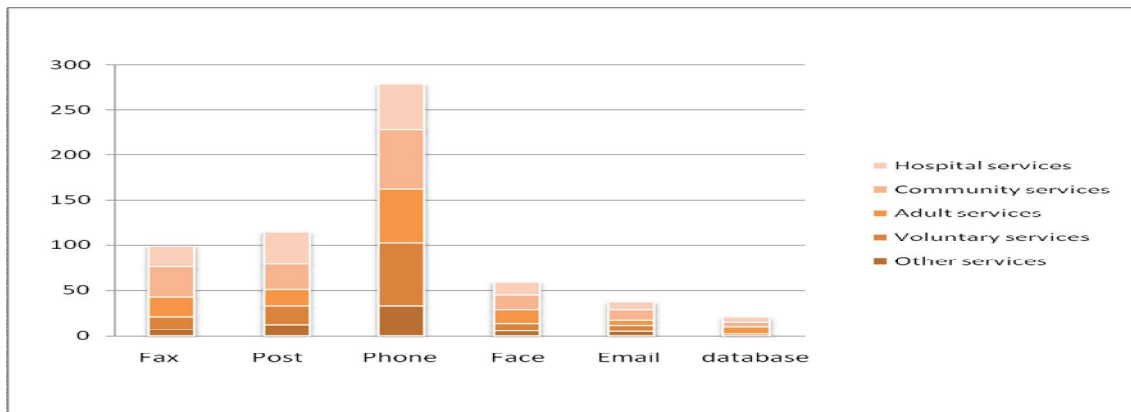


Figure 3: How professionals make their referrals

In interviews feedback highlighted that current processes are time consuming and inconvenient. They would welcome sharing of information about how to make referrals to other services. It was encouraging to see that staff members were aware of voluntary and additional services with over 50% of those completing the questionnaire saying that they referred service users to voluntary organisations. Please see Figure 4.

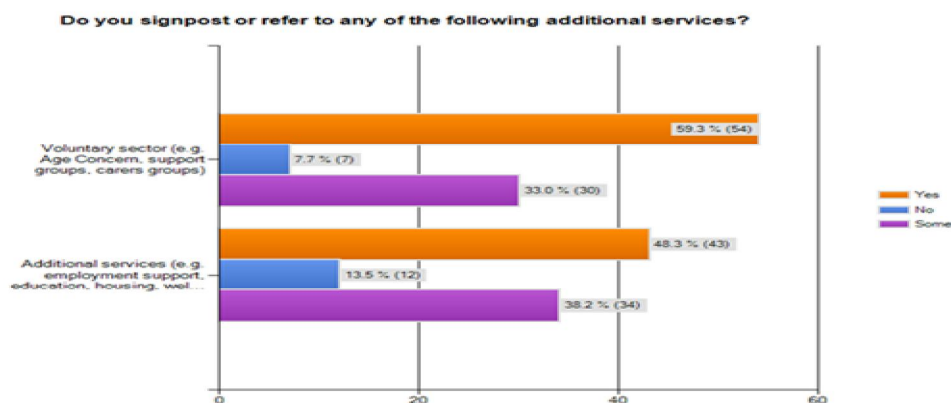


Figure 4: Referrals to the voluntary sector

There was general agreement, that whilst support services are a vital aspect to general health and wellbeing, the main obstacles to making a referral were lack of time and knowledge of organisations/services offered. One to one discussions highlighted again that staff found it hard to keep abreast of the vast amount of agencies. This led them to refer service users to high profile groups such as Age Concern or the Parkinson’s Disease Society but were less knowledgeable of smaller support groups or local organisations. The Information Prescriptions project offered by Nottinghamshire County were suggested as an example of a facility which offers advice and information on neurological services. There is at present no dedicated service in Nottingham City

“It can be hard to find the right organisation and could take a while to find the right one – this causes extra work for staff and delays for patients”

Data and systems

Another barrier to providing the best services was that it was not always clear if a service user was already receiving another service. This problem is confounded by the services using unique data bases to hold their patient information. Twelve different systems were reported by the 90 respondents. These data sets are rarely shared. Many teams only have access to their own organisational data and this can lead to delays or additional time before a patient can be treated. A total of 56 (68.3%) of the 82 respondents said that they experienced problems in making or receiving referrals due to a lack of access to other organisational database systems. Table 1 shows the main areas that could have been avoided if they had shared access to data base information.

Reasons	%	N = 53
Duplication of services	60.4%	32
Lack of current/past intervention information	73.6%	39
Lack of personal patient information	62.3%	33

Table 1: Main problems faced by not sharing databases

“It would be great if we had access to blood results etc. before going out to see a patient –it would allow my team to plan ahead for visits and save a lot of time wasting for us and patients”

At present there are long term national projects (NHS Connecting for Health) as well as local initiatives attempting to implement a pro-active use of systems which will make improvements in communications and influence future solutions.

Reflections on a specialist referral point to services

Although the majority of those surveyed were in favour of clearer pathways to services it was interesting to note that in interviews, staff said that even if a specialist referral point to services was established they would still use a combination of personally established routes of referral and only use a new service when unsure. This cautious approach is possibly due to the number of NHS projects that have started only to be removed after a couple of years. However if professionals do not use a new service they may never expand their knowledge of services available to patients. Alternatively there were a number of professionals who said they would use a specialist referral point but there were concerns over the training that Service Advisors working at the ‘specialist point’ would receive. The interviews highlighted that any changes to procedures would need intensive training across all sectors if front line workers are to appreciate the advantages.

“It can be hard to know where to refer neurological patients to in the community especially those who find it hard to attend hospital appointments – a neurological information point would make it easier to find out choices available and would give patients a better experience”

It was generally agreed that communication across all sectors needs to be increased to build up closer working relationships and increase knowledge. Those based at multi team buildings such as Mary Potter Health Centre felt that communication was less of a problem as they could interface with other teams and the wealth of knowledge was shared and extended whereas at smaller centres staff felt more isolated saying communication could be a longer process and a pull on resources. It was felt that a specialist referral point could improve interaction between teams.

“Nursing roles in community are difficult due to lack of access to medical information. It is time consuming to get basic patient information and affects patient care, I am often unsure if other services have already made a referral and I often find they are not aware of our input making liaison difficult, also lack of medical information on hospital discharge makes assessment difficult”

Conclusion

This survey of professionals across health, social care and voluntary sectors, highlights that improvements in service organisation are needed to ensure that access to appropriate services and treatment for service users can be achieved. Most of the respondents knew that a range of services were available and most knew how to access them. However there were a number of obstacles that made the procedure time consuming and difficult. Some of these are not easily achieved by the NIAP; such as joint data bases and access to patient information across organisations. However others such as setting up a specialist referral point are achievable. The health and social care staff that completed this survey were only a very small sample of the work force, but they provide an indication that they are open to proposed developments and not resistant to change. They appear keen to embrace a specialist referral point if it is to be long lasting and help their service users. If the specialist referral point is to be a success it is evident that service advisors will need to be trained and have ongoing support from neurological professionals.

“Neurological conditions have not been at the forefront and have been overtaken by higher profile conditions such as COPD and heart failure. Now that neurology is being highlighted by guidelines such as NSF-LTC we are having to make improvements to services and need clearer pathways to reflect care and meet these needs”

References

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Gladman et al 2008 Rehabilitation services for long term conditions: what works and what is available? (last accessed Jan 2010)
<http://www.sdo.nihr.ac.uk/files/adhoc/132-132-research-summary.pdf>

NHS Connecting for Health (last accessed Feb 2010)
<http://www.connectingforhealth.nhs.uk/>

Appendix 1: Grant Holders and Trial Steering Committee members

Name	Organisation
Julie Folkett	Parkinson's Disease Society
Dr Pip Logan	University of Nottingham
Gill West	Parkinson's Disease Society
Julia Pollard	NHS Nottingham City – CitiHealth Nottingham
Sally Parker	NHS Nottingham City – CitiHealth Nottingham
Anna Marriott	NHS Nottinghamshire County
Pauline Greaves	Multiple Sclerosis Society
Paul Watts	Parkinson's Disease Society
Mandy Shiel	Nottinghamshire County Council
Helen McCloughry	NHS Nottingham City – CitiHealth Nottingham
Annabel Taylor	NHS Nottingham City – CitiHealth Nottingham
Mo fowler	Progressive Supranuclear Palsy Association
Joanne Williams	NHS Nottingham City
Jake Jacobs	Nottingham City Council
Julia Webster	Nottingham University Hospitals
Cheryl George	NHS Nottinghamshire County & Bassetlaw PCT
Alison Attenborough	Nottingham University Hospitals
Nina Marshall	NHS Nottinghamshire County

