

Manchester Information Prescriptions Pilot

Stakeholder Event Report

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Introduction

This report includes the finding of a stakeholder event, which was held on the 03/07/07 to launch information prescriptions (IP) for Parkinson's disease (PD), and Multiple Sclerosis (MS).

The aim of the conference was to present two information prescriptions and to gather information on the following topics as well as raising the profile to a wider audience and enlisting support from other stakeholder.

Information Prescription being presented by Councillor Curley



Aims:

1. To explore current information provision
2. How current information is accessed
3. How appropriate current information is
4. What information could be included in an IP
5. To explore the format of an IP
6. To explore most accessible options for delivery of an IP
7. Enlist the help and support of stakeholders

Who attended?

The event was attended by 80 people including people with Long Term Conditions, carers, members of the Parkinson's Disease Society (PDS), a member of the Multiple Sclerosis Society (MS), Health & Social care professionals including, Clinical leads, social workers, Team Managers and Manchester Advice.

Facilitators were allocated to each table that facilitated the group work and recorded feedback on flipcharts and notepaper during the sessions.

People at the conference



Group work session



Task 1 – What current information is provided?

Service users and Patients in general felt that information in both Health and Social Care was very scarce. Some groups said there is no set pattern to information and it was very difficult if you didn't know what to ask for.

Other comments made from people who attended the event said that if they do ask for information, it is very slow and they then end up doing it themselves or going through family support networks or websites, which can be quite frightening.

Patients and carers reported having little or no information at diagnosis, certainly nothing written down, and being left to look it up for themselves.

One group said that they only have access to basic information and if they need more they lack confidence to ask. People on the same group said there is a severe lack of information and this makes them feel abandoned after they have been diagnosed with a LTC. It was felt that Hope hospital give out good information but it was too far to travel particular when you don't have transport.

It was commented from one group that Social Services make appointments and then cancel and very little information is offered to them unless they have been allocated a Care Manager. This group said "if you don't ask for information, professionals don't offer and because you lack confidence you don't always ask" This then means you don't have access to any information and when you have no family member this can result in losing confidence and afraid to ask in case they think you are asking too many questions. This some user said makes them feel very isolated and not in control of their life.

Another group said that you can access some health information on the website but this is sometimes very time consuming and are not always sure the information is correct.

It was felt that the MS Society produces good information but that there was no support to explain or access the information when they need it.

It was also felt that there is a lot of information about AIDS but not a lot of information about HIV and what does exist is very generic. One person said they were diagnosed with their condition about 8 years ago and up to today's date still has very little knowledge about health and social care services. One person complained that Social Services made it very difficult and complicated to access services.

In general most people felt that Information is currently given in a range of different ways:

1. Verbally – discussion
2. Carers guide
3. User guide about support groups
4. Leaflets and resources

5. Booklet
6. NHS Direct
7. Telephone

Carers felt they were given information verbally but felt poorly informed and they were often the people who researched the condition most to understand and cope with symptoms, which often lead to misunderstandings between them and the person they care for.

Professional stakeholders felt they were unable to give information before a diagnosis is available. Social Care professionals were often not involved in the care pathway until the later stages even though people would benefit from some preventative advice early on.

Some Professionals reported giving information on contact however, many users felt they had to ask for information and needed to be self-directed learners. This was difficult as there were uncertainties about what they should know in order to ask the right questions.

Task 2 – How information is currently accessed?

One group said they accessed information from the NHS direct either through their website or help number. It was felt that Health and social care professionals could sometimes provide information once they had been referred to them but that information was required whether professionals were involved or not in their care.

One group said that Health and Social Care's information has slightly improved but that they tend to rely on their views and knowledge. Specialist nurses provide information but it was felt that users and patients are told what they need rather than be asked what information they require.

One group said they rely on getting information from other patients in a waiting room in a GP surgery as the Doctor doesn't have the time to go through your information needs in the appointment time allocated. The same group said that they often rely on leaflets and posters that are displayed on the waiting room wall when they are waiting to see their GP.

One group said that there are a variety of routes and formats required but not everyone can access the Internet and the information is not always up to date.

HIV: local voluntary groups are not always responsive when you ask for information and it can take 8-10 months for them to respond to a request for information or support from service users.

One group said that hospitals might sometimes tell you about aspects of your condition that your GP may not be aware of.

Another group said if you have a Home Help they sometimes get information for you but not everybody has a home help.

Task 3 – How appropriate is the information you currently receive?

One group said that sometimes “Health staff doesn’t give appropriate information and they use too many big words and I don’t understand what is being said”.

One group said “the Internet contains a lot of incorrect and spurious information and it can be very frightening”. The same group said that leaflets were very general and not very specific to the person or their problems.

One group said, “The MS society had very good information but needed some support with the information about their condition”. The same group said “HIV information is too generic and very scary because it deals with end of life issues for full-blown aids”. It was felt by this group that information about HIV is very scarce and you only get information when you are at death’s door.

One group said that they don’t trust the information from their GP’s as they are always busy and the patient feels that they say anything to move on to the next patient.

One group said, “We would not know how appropriate the information is, as we have no idea where to begin to validate the information”.

One group said “we need support especially if we had an information prescription”. The group said, “We need to feel we are not alone and have contacts but an information prescription might give you this”.

One group said, “if you have been diagnosed with a long-term condition, the information is not appropriate”. It was felt that support groups do not open doors for people who was diagnosed a long time ago and there is definitely an information gap in this area.

Task 4 – what information should be provided to people with LTC's

One group said they would like information on Health such as adapted housing and equipment services. In Social Services information is needed about services available such as individual budgets and the flexible use of funds to meet changing needs. It was felt by this group that information should be available on prevention and re-enablement services.

One group said “information is needed on how to get support workers and also information about living rights”.

One group said that lifestyle information is important to help us self manage our condition especially around support to reduce stress in life, which can be a trigger for exacerbation of symptoms. The same group said that information should be more available about how to access social services support and the access criteria, which is likely to be a preventative measure.

One group said that they would like information that recognises changing needs and that is offered at the right time and that you should not have to ask.

More information is required on coping with a LTC (Well-being) that is specific to the person and not solely the condition.

One group said that health should provide information about what places are accessible because if you cannot gain access then there is no point in attending. The same group said that Social Services and housing are not linked and this is an oversight. The group also said that they would like information around advocacy such as an independent person to advice such as drawing up wills.

One group said they would like information about their diagnoses and also medicine information such as how to identify different tablets etc. The same group said they would like access to information about who to contact within a service and helpline numbers.

Another group said they would like information about their rights and what they are entitled to.

Other information required: -

1. How to access services
2. How to get in touch with the local support groups
3. Drug related information
4. Information at diagnosis
5. Variety of formats as there may be problems reading leaflets.

Task 5 – Structure and accessibility of IP's

A wide variety of formats and media should be considered and how they could be quality assured and maintained. Individual differences in learning style and cultural differences in health seeking behaviour flagged the importance of personalising information provision.

Ethnic minorities – translation into other languages should be available and content needs to be checked as people have different health seeking behaviours.

Disability – Media and style need to be considered to accommodate physical or sensory impairments and learning difficulties (Braille, audiotape, DVD).

The IP should provide a signpost to a directory or log a patient's information journey, like a passport maintained by a patient or carer.

One group said "it would be good if you could get your information prescription from your doctor's surgery or off the Internet". The same group said bingo clubs would be a good idea or somewhere like churches especially for different cultures. Also social services or the television was other suggestions within this group.

Two groups said the chemist or GP surgeries, Consultants, walk in centres, Care Managers, Health centres and District nurses would be a good place to get your IP.

One group said at diagnoses probably by the specialist nurse but felt it was unlikely that the GP would dispense it. Neuro voluntary sector organisations would be good like Basic Centres or local libraries or chemist.

Another group also said community resource centres and health centres. The same group said at diagnoses by the consultant or by staff working in the hospital. Could also be advice workers on a one to one basis or in a one stop shop.

One group said if they had access to the right information on the IP then they could challenge GP's and other staff about their rights.

HIV should be a nurse working with HIV/AIDS consultant physicians but community options should not be considered due to stigma of disclosing that you have HIV. Maybe somewhere in the gay village where there is no stigma attached.

For professional stakeholders it was felt that the IP is a great idea and would help them to educate themselves on the information available and to know what is happening. The IP could be used to flag up a gap in information and where more work is needed to develop new information resources.

General comments from the group work

1. Similar types of information need to be accessed at different stages of the disease progression
2. An additional category of information should be made available for patients prior to confirmation of a diagnosis of a LTC.
3. Patients and carers should be able to talk through the information they receive with a health or social care professional, or trained support worker.
4. Information should be designed to enable patients and carers to understand how services or the system works in order to enable them to participate fully in organising their health and social care.
5. Information prescriptions should include information on local as well as national services
6. Information should be geared to areas where the services differ

Most of the groups felt it was not always useful to think of personalising information by using stages, as stages were not clearly separated and issues relevant at one stage were often important in the next, people's information needs vary depending on personal circumstances, and some people like to have all available information from the outset, whilst others prefer not to know much at all and just deal with issues as they arise. One problem is that people may expect to experience all the symptoms of their condition at some stage in the course of their illness which may not be the case and this would require them knowing irrelevant facts. There is a case for only providing information relevant to problems as they arise.

Another stage should be added for the period before diagnosis of a LTC's. The process is often long drawn out, confusing, with no indicative tests readily available, and this is marked by feelings of uncertainty and anxiety.

It was generally felt that information alone is not enough; there is a need to have someone available to newly diagnosed patients especially if they access information, which is upsetting.

Recommendations made were to have printed information available on diagnosis about the condition with details of who to contact with questions and answers.

Consideration would need to be given where no specialist service exists, a GP, or a practice nurse should then prescribe information.

People reported receiving better information once they had been referred to a dedicated service, however, information will need to be applicable where there is no specialist service in the area.

Information should be available at diagnoses so that it can be taken home to read at leisure and, importantly, an opportunity to talk this through with a professional.

A suggestion was that the Nurse Specialist could co-ordinate information giving and tailor what is needed by asking patients and carers what they know and what they want.

Ensuring local access, possibly at the outpatient clinic ('a one stop shop')

To empower patients and carers they would need support to know what is available and to be supported in their learning by health professionals. This would require training of staff as the effectiveness of IP's may be dependent on the communication abilities of the person is at delivering them.

IPs should be dated and the issuer identified, and details of the way accuracy has been assured issued with the IP.

The procedure of issuing IPs should be monitored and reviewed, perhaps by carrying out a satisfaction survey.

It was important to provide choice of formats to be as inclusive as possible.

Stakeholder evaluations

The evaluation of the event was generally very positive and most of the evaluations forms handed back in had comments such as “very interesting day found it very easy to understand”. One person commented that they were delighted that “at last Health are listening to what we say but hope they act on it”. Another person said “It was great to meet other people and promote my ideas to improve well being for all”. One person commented that the venue was excellent and well organised and another person commented that the information received was very informative. Another person commented “ I didn’t know much about Information Prescriptions so found it very useful to hear about this and be involved”

One person felt that the background noise levels made it difficult to hear what was being said in the group work particular in the second session, which was difficult to follow. Another person commented that the presentations were long and they would have preferred to do more group work rather than listen to people talking. Another person commented that more people needed to participate in the group work sessions. One person commented about the venue particular around the disabled facilities such as access into the building and the toilets were to far away and could only be access by lifts. Three people commented on how bad the parking was at the venue and asked that the organisers take this into account when arranging things like this for service users. One person said a longer break was needed and that there needed to be more service users at events like this. Another person commented about better lighting at the venue.

Some recommendations made on the Evaluation Form were thing such as “the notes from the work group sessions should be distributed to everyone who attended”. Another person said, “The information should have been sent in advance so that our responses could have been considered more”.

Professional stakeholders feeding back said they appreciated the opportunity to network and to engage in open discussion with real issues.

All stakeholders were asked to evaluate the event and to indicate if they would be happy to work with the project team to develop an IP for people with LTC’s. Many were happy to be involved but were unsure of their role. However, eight forms were handed back in from service users, patient and professional stakeholder who expressed an interest to join the Steering group.