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to delivery of a person centred relapse service

B Porter, F Matheson, J Chataway and others

1. Audit and service evolution

Steps to Service Improvement and Modernisation

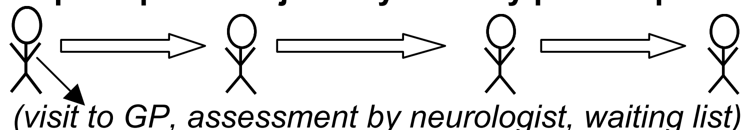
(1) Map patient's journey
(2) Clinical audit
(3) Pilot
(4) Randomised Controlled Trial
(5) Care pathway
(6) Philosophy of care
(7) Encouraging self-management
(8) Decision making within a concordance model

No 1: Map the patient's journey

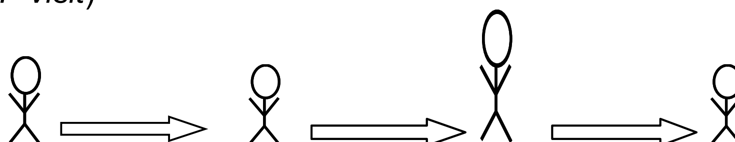
An important first step in matching capacity and demand is establishment of the patient's journey. The application of a modernisation framework can help establish baselines and set targets for objectives as outlined in Box 2[11].

Box 2 Mapping the patient's journey

- **Define and agree patient group**
  (all MS relapse patients on admission list)
- **Define and agree the scope of the stage** (first and last step)
  (referral from GP – date of first infusion)
- **Identify all staff involved**
  (all clinical and clerical staff)
- **Map the patient's journey and any parallel processes**



  (visit to GP, assessment by neurologist, waiting list)
- **Identify those stages that do not add value**
  (*GP visit*)



- **Identify the bottlenecks and constraints**
  (*difficult to access services, GP-neurologist long wait, MS relapse low priority to admissions team)*

Reduce the number of steps involved

No 2: Clinical Audit

The completion of clinical audit exercises can provide a very useful structured mechanism to review the quality of everyday care provided to patients. Clinical audit addresses quality issues systemically and explicitly, by providing reliable information about the quality of clinical services and highlights the need for improvements[12] .

Table 1: Why do we need audit?

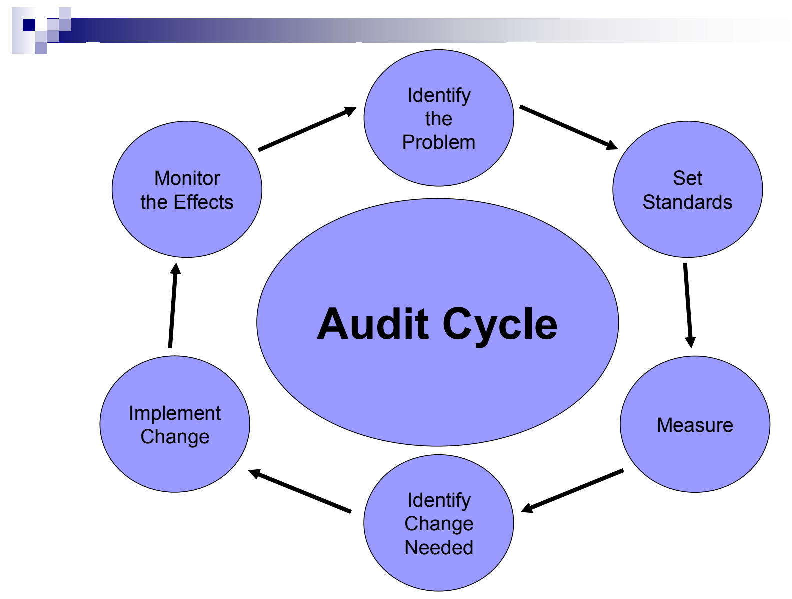
• To ensure that comprehensive clinical protocols are developed, implemented and monitored
• To ensure Trust/Directorate wide clinical standards are developed, implemented and monitored
• To ensure that where clinical standards/protocols exist they are subject to clinical audit
• To ensure that clinical audit projects are part of an agreed programme of work that is linked to the directorates' clinical governance priorities
• To ensure that clinical audit activity is directed towards improving the quality of services for patients
• To focus on implementing the recommendations of clinical audit projects, to ensure that clinical audit activity leads to tangible improvements in patient care.
• To listen to patients and their carers; to seek their involvement in setting priorities for clinical audit

(Adapted from the NHNN/ UCLH Clinical Governance Bulletin, Vol 1, 2004)[17]

Using audit to facilitate change

The application of audit within an audit cycle model (figure 2) can help measure steps and waiting times involved for patient groups. The audit findings from the National Hospital for Neurology and Neurosurgery (NHNN) are summarised in Box 3.

Figure 2 Audit Cycle



Box 3 NHNN Audit findings

- Patients were admitted to 5 neurological inpatient day units
- Long delays to receipt of treatment
- Delays between relapse onset and receiving intravenous treatment ranged from **2-19** weeks
- Mean delay was **6.1** weeks

The audit process had identified unacceptable delays and provided objective evidence to support the need to implement change.

No 3: Pilot

Using a pilot study to test change and identify potential problems

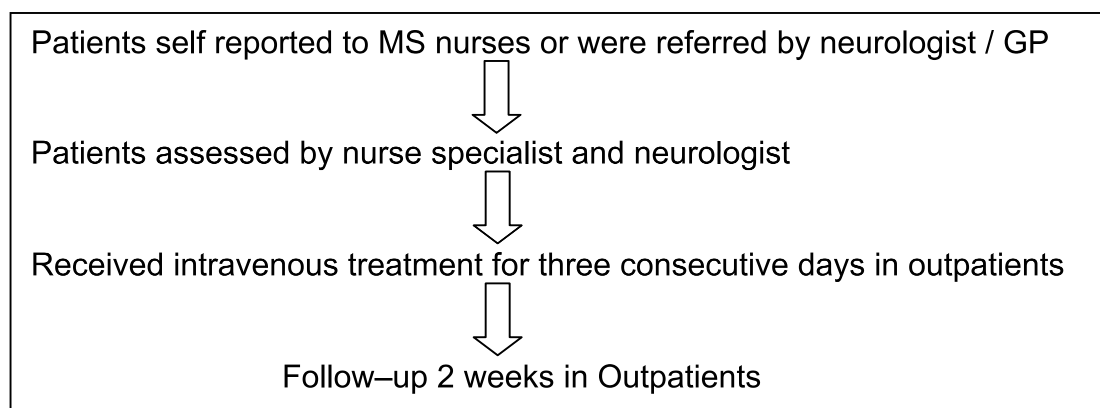
The clinical audit identified the need to change service delivery. The completion of a pilot study provided an opportunity to explore potential problems and ensure that teamwork, processes and systems worked effectively and reliably. The pilot study was performed within a robust clinical governance framework.

The pilot study aimed to:

- Demonstrate the feasibility of administering intravenous methylprednisolone safely within an outpatient environment
- Record needs of patients using the service to help plan service development
- Collect evidence on patient self -referral mechanisms
- Collect patient views to ascertain what they value at time of relapse

The pilot study streamlined the care pathway minimising steps that did not add value, avoiding bottlenecks and constraints and reducing the number of steps involved.

Pilot clinic care pathway:



The pilot study results are summarised below:

- 30 patients were treated in the pilot study
- Demonstrated safe administration of IVMP in outpatients
- Responsive service waiting time range **1-13** days mean **6** days
- Demonstrated high levels of accuracy in patients self-reporting
- Demonstrated high levels of patient satisfaction
- Provided the base for a number of other research questions

From a Pilot Study to a Randomised Controlled Trial

The pilot study provided a solid evidence base in which to modernise and change existing service provision. The changes implemented following the pilot study are summarised in Table 2.

Table 2 Evolution post pilot clinic

- Established administration of IV steroids in outpatient arena
- Development of a bespoke relapse suite (grant funded)
- Establishment of patient self-referral mechanisms
- Development of a tele-triage system
- Development of care pathway within a clinical governance framework

The pilot study had demonstrated that intravenous steroids could be administered safely within an outpatient environment. However, this model requires the patient to visit hospital when they are feeling least able. In order to address this issue, the team explored the literature for evidence to support a home delivery service model. The literature search identified that there was no evidence to support a home care delivery model in MS; and that there were no outcome measures to assess what people deem important in management of MS relapses.

In order to examine this area the team were successful in obtaining a grant from the MS Trust to complete a randomised controlled trial comparing outpatient versus home delivery of steroids. The full methodology is discussed in the trial paper[1]. The first stage of the project involved the development of a psychometrically robust outcome measure scale the MS Relapse Management Scale (MSRMS) . The trial paper[1] outlines the detail whereas Table 3 summarises the main design points and findings.

No 4: Randomised Controlled Trial

Table 3 Trial Summary

Design

- Randomised controlled trial (138 patients)
- Primary outcome measure: MS Relapse Management Scale
- Specialist assessment and follow-up
- Non specialist delivery of intravenous steroids

Results

- Significant difference in **co-ordination of care** in home arm-that is:
  convenience of treatment
  convenience and timing of treatment
  comfortable setting
  comfortable passing the time
  calm and relaxed environment
  treated in a comfortable position

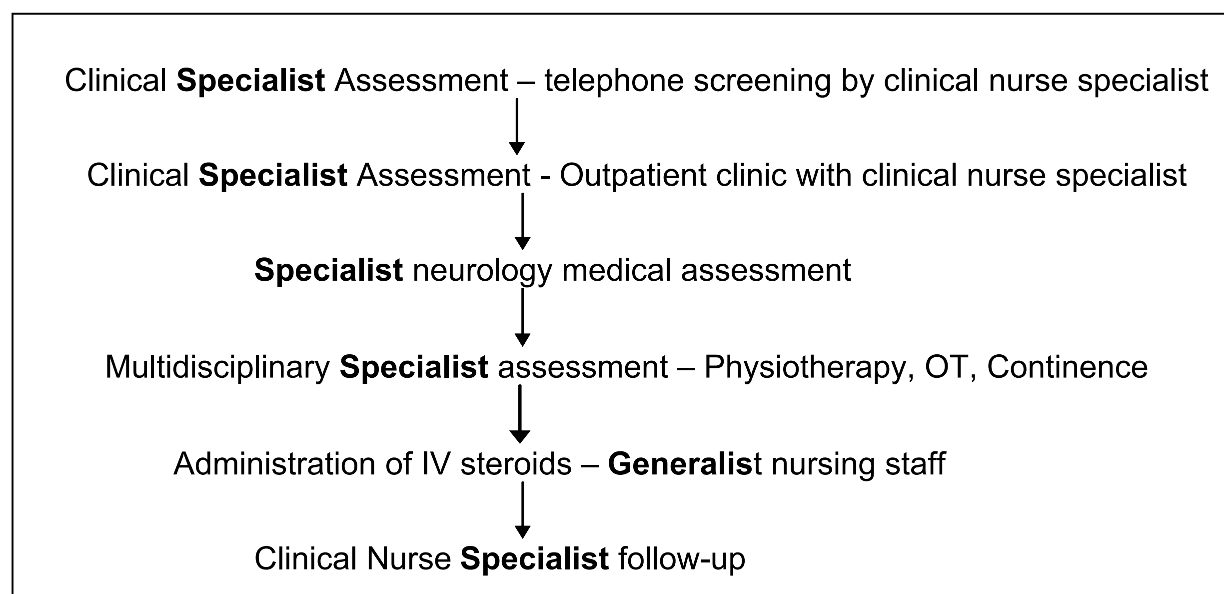
- Cost neutral if not cheaper than outpatients
- Home is patient's preferred option

Summary

Over 5 years the NHNN relapse service has evolved from an **inpatient** to an **outpatient** service and more recently demonstrated that ultimately a **home** based service is superior from the patient's perspective. This work is an example of multidisciplinary, across boundary team work supported within a culture of innovation and improvement and within a robust clinical governance framework .

No 5: Care Pathway

In order to standardise relapse management within an evidence based model a care pathway was designed. The specialist and generalist components of the pathway are summarised below:



The relapse care pathway considers in detail the needs of each individual. However, a number of clinical factors may preclude patients attending clinic and some specific points should also be considered.

Clinical factors to consider:

- Patient deemed to require hospitalisation due to severity of symptoms
- History of allergic reactions or severe side effects including abdominal pain or psychiatric reactions to steroids
- Patients must not have identifiable low mood with suicidal ideation demonstrated on assessment using appropriate validated depression scales e.g. Hospital Anxiety and Depression Scale (HADS)
- Excess use of non steroidal anti-inflammatory drugs or alcohol

Social factors to consider:

- Appropriate services may be available more locally
- Patient is deemed a child or adolescent – local policy for treatment in an adult arena may apply
- Patient unable to provide own transport or has difficulty getting to clinic
- Patient has inadequate carer support to attend appointment
- Disruption and impact on role/ family/dependents by attending clinic

No 6: Philosophy of Care

PwMS should be supported to become expert in self-management where possible. In terms of relapses, people should be given ***information*** regarding general health factors, such as infection, that may influence the risk of relapse. PwMS should be advised how to detect relapses and what to do if new symptoms occur, including how to ***self refer*** into primary or secondary care clinics.

In the event of new or increased symptoms people with multiple sclerosis should be able to identify and ***contact a professional*** from their healthcare team who can advise them or direct them to the most appropriate local service.

Management of acute relapses should not just be limited to corticosteroid therapy but should be ***comprehensive***, tackling all aspects of the relapse. Practical supportive measures, such as the provision of care or equipment, may be essential and should not be forgotten. Symptomatic treatment for new symptoms (e.g. pain, spasticity) from a relapse may also be required.

Functional recovery from a relapse may be facilitated by ***multidisciplinary input*** from neurological rehabilitation services. This input should run in parallel with any medical treatment.

A randomised controlled trial found a ***multidisciplinary rehabilitation*** approach to be superior to a standard ward routine in people with multiple sclerosis receiving intravenous corticosteroid therapy[13.] ***In-patient rehabilitation*** has also been shown to be useful in relapsing remitting multiple sclerosis particularly in people with incomplete recovery from relapses with moderate to severe disability[14].

No 7: Encouraging Self-Management

The majority of people with Multiple Sclerosis (PwMS) want to be involved in their overall management plan; however, they must be supported to do so. In addition to good communication, PwMS require timely, accurate information and support. Education and support are an ongoing part of management from diagnosis onwards to ensure that individuals are enabled to actively participate in their own care.

People with MS are often expert in detecting and anticipating changes in their health and wellbeing. Health and social care professionals should support people with MS to become expert patients by aiming to give the person the knowledge, skills and confidence to participate actively in all aspects of their own care. PwMS bring a wide range of skills and play important roles in management strategies as shown in Box 6 and Box 7.

Box 6

Patient skill set	**Clinician skill set**
Experience of illness Social circumstances Attitude to risk Values Preferences	Diagnosis Disease aetiology Prognosis Treatment options Outcome probabilities
Management strategies	
Patient's role	**Clinician's role**
Monitor symptoms Report symptoms Manage the disease on day to day basis	Consultant Interpreter of symptoms Act as a resource Offer treatment suggestions

The key requirements to self management of a chronic condition are summarised in Box 7 [5]

Box 7 Requirements to self-manage a chronic disease

- Knowing how to recognise and act upon symptoms
- Dealing with acute attacks of the disease
- Making effective use of treatments/medicines
- Comprehending the implications of professional advice
- Establishing a sleep pattern and dealing with fatigue
- Assessing social and other services
- Managing work
- Accessing leisure activities
- Developing strategies to deal with the psychological impact of the illness
- Learning to cope with other people's response to their illness

No 8: Decision making within a Concordance Model

People are not passive recipients of prescribing decisions. They have their own views about medicines, how they should be used and how medicine taking fits in with their daily lives. These views are based on a personal set of beliefs and understanding influenced by factors including the experience of family and friends, culture, education and social circumstances. They may be based on an incomplete understanding of the nature of the illness and the proposed treatment or at odds with scientific evidence. In other cases they may be based on a patient's own experience of medicine taking and their knowledge about what fits in with their lifestyle.

Studies of doctor-patient communication suggest that these beliefs and views are not often explored in prescribing consultations. Studies have shown that doctors underestimate the degree to which they **'instruct'** and overestimate the degree to which they ''**consult''** and elicit patient's views[16].

Research, surveys and people's individual stories have shown that people are making conscious decisions about whether to take medicines based on their views, beliefs and experiences. People are therefore more likely to benefit from therapy when they understand the diagnosis and treatment, have had a chance to discuss their views and beliefs and are actively involved in decisions about management of the condition.

It is increasingly recognised that the key to making better use of medicines is involving people as partners in decisions about their medicines – sometimes described as concordance. ***Concordance*** is a new way for prescribers and patients to agree about medicines together. It ***measures the consultation process*** and looks for an alliance to be struck between prescribers and patients – an agreement on how medicines will be used, after both of them have had their say. In order to work within the framework of concordance (Table 4) health professionals must accept the principles of the 5 long term goals summarised in Box 8.

Table 4 Concordance framework

CONCORDANCE A process of prescribing and medicine taking based on partnership		
Patients have enough knowledge to participate as partners	**Prescribing consultations involve patients as partners**	**Patients are supported in taking medicines**
• Knowledge empowers patients to manage their own health • Patients are helped to access information about their conditions, and the recommended medicines, which is: ▪ based on their needs ▪ clear ▪ accurate ▪ sufficiently detailed	• Patients are as involved as they want to be in treatment decisions • Patients are invited to talk about their views on the diagnosis and the treatment options, and to voice any concerns • In light of this, prescribing decisions are made jointly between professionals and patients • Professionals explain the agreed treatment fully • Patients are invited to talk about their understanding of, and ability to follow, treatments	• All opportunities are used to discuss medicines and medicine taking • Patients are asked for their views on how their treatment is progressing • Information is effectively shared between professionals • Medications are reviewed regularly *with* patients • Practical difficulties in taking medicines are addressed

Box 8 Concordance model in relapse management

1. Health professionals must view prescribing as something they do jointly with patients
   The person with MS makes the decision of whether to attend the relapse clinic or not

2. Patients expect to be involved in decisions about their medicines
   The final decision to proceed with steroid treatment is made by the person with MS

3. Resources available to help patients with different needs to understand their medicines
   A patient information booklet, oral information and website www.msdecisions.org.uk are available

4. Different health professionals work in partnership with each other and patients
   A combination of multidisciplinary team members from primary and secondary care work in partnership to assess and deliver treatment

5. Services operate to support patients taking medicines
   A specific relapse clinic, pharmaceutical expertise and nursing help line is available to discuss treatment

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Key steps to delivery of a person centred relapse service.
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