

# The Development of a Health Information File for People with MS in the UK

Cray F, Franklin K, Quinn D, Wilkinson D, Gaughan S, Barraclough R, Smith A

## INTRODUCTION

The National Service Framework for Long Term conditions (DoH 2004) and Expert Patient Programme (DoH 2004) highlight the need to improve the quality of care for people with MS (PwMS) and the importance of developing more effective approaches to self management of this long term condition.

It is well recognised that PwMS are likely to encounter a variety of health and social care professionals, each of whom will retain separate records. For some patients this can lead to conflicting advice interventions, duplication and confusion. In addition, about half of all PwMS experience cognitive difficulties including impaired ability to learn, remember, plan, concentrate and assimilate information quickly (NICE 2003).

As a MS Specialist Nurse group we embarked on an initiative to develop a tool that will help PwMS better manage their care and promote independence.

## METHOD

The East Midland MS Specialist Nurse Group developed and produced a Health Information File designed to help PwMS (and their carers) become more involved in their MS management plan. Designed as an A5 ring binder with sections in which the following can be recorded:

- Names/contact details of all relevant health and social care professionals.
- Health and social care communications in which the details of any contact can be recorded.
- Medication in which details of treatments are recorded.
- Medical history.
- Future health appointments.
- Symptom diary.
- General MS related information.

The file is designed to be retained by the person with MS (or their carer) and taken to each health or social care consultation or interaction so that the relevant professional can update the file as appropriate.

It is believed that use of the Health Information File will:

- Serve as an aid to structured care.
- Help educate PwMS, carers and healthcare professionals in the principles of quality care through effective communication.
- Involve PwMS and their carers more closely in their MS management plan.
- Facilitate continuity of care.

The file has been evaluated in a pilot, open study by PwMS.

## EVALUATION RESULTS

The Health Information File was evaluated by 108 PwMS who used it for at least 6 months and in some cases 1 year. At the end of the evaluation period 53 PwMS completed and returned a questionnaire outlining their attitude to and opinion of the Health Information File. Data taken from the analysis of these questionnaires shows:

- 75% (40) of the 53 respondents indicated that they had used the file.
- There was no apparent difference in usage according to the duration of the respondent's disease (see Fig 1).

Those who used the Health Information File were also asked to identify those aspects of the file that they considered the most and least useful:

- The most frequently cited useful aspect of the file was that it provided a more precise record of MS symptoms.
- Its use as an information source was also highlighted.
- The most negative aspect of using the file was seen to be remembering to complete it (amongst those who did not use the file this was the most commonly cited reason).

Respondents were then asked if they agreed with a series of questions highlighting the possible benefits that the Health Information File offers to people with MS. The responses are shown in table 3. It is interesting to note that:

- The most frequently perceived benefit of the Health Information File was its ability to serve as a 'prompt', reminding people what questions they needed to ask the different healthcare professionals they encountered in the course of their healthcare (this is in accord with the most frequently cited useful aspect of the file 'more precise recording of symptoms').

Respondents were also asked some further questions about the Health Information File (table 4).

- 97% (39) of those using the file would continue to use it after the assessment.
- There was very limited enthusiasm for an internet version of the file.

## CONCLUSION

The results from this pilot study show:

**There is a need amongst PwMS for a Health Information File of this type (75% used it and 97% of those said they would continue to use it after the study period).**

**The Health Information File was perceived as useful irrespective of the length of time since diagnosis.**

**The Health Information File was seen as a useful tool, acting as a reminder when discussing their care and facilitated better communication between PwMS and those professionals responsible for their care.**

**The Health Information File was also found to be useful as a single information source.**

**Some PwMS in the study found difficulty remembering to use the Health Information File.**

## Direct quotes from PwMS regarding the Health Information File:

*"Keeping a note of any symptoms between hospital visits"*

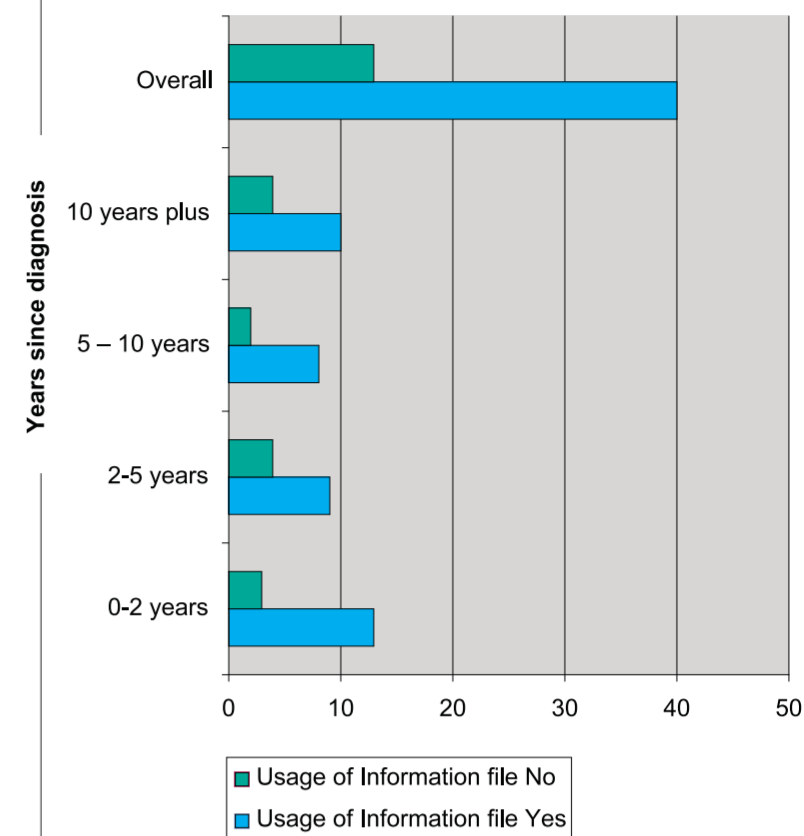
*"Everything written down for everyone to read as I have memory problem so cannot remember what I have been told"*

*"Having it when visiting a new Neurologist, I had my history in it"*

*"A reference when I experienced symptoms"*

*"It shows a history of the help I've received"*

**Table 1** Duration of illness of questionnaire respondents to usage of Health Information File



**Table 2**

Most useful/least useful aspects of Health Information File amongst PwMS using it

Most useful		Least useful	
Aspect	mentions	Aspect	mentions
Recording symptoms	16	Difficult to remember	5
Information source	5	Print small/difficulty writing	3
Aide memoir (injection, OP appointments, contact details)	6	Too many sections	1

**Table 3**

Respondents opinion on how Health Information File helps

Benefit statement	PwMS responding positively				
	0-2yr	2-5yr	5-10yr	10yrs+	Total
The Health Information File helps:					
Communication with different healthcare professionals	9	7	6	5	27 (67%)
Prompts me to ask questions at different professional appointments	11	8	7	7	33 (82%)
Gives me more control over my healthcare	8	5	5	9	27 (67%)
Helps me to manage my condition	8	5	7	7	27 (67%)
Total Health Information File users	13	9	8	10	40

**Table 4**

Respondents were asked:

Question	Number responding positively
Will you continue using the Health Information File	39 (97%)
Would you use an 'internet' version of the Health Information File	17 (42%)

## FUTURE

We plan to continue the development of the Health Information File for PwMS with a particular focus on:

- Refining the structure and content of the file on the basis of feedback from PwMS who have an opportunity to use the file.
- Investigating options for producing the file and their respective costs and thereby increasing the access of PwMS to the Health Information File.
- Obtaining the views of other professionals providing care for PwMS on the use of the Health Information File.

## SUCCESS

We believe that our project will have successfully concluded if:

- All PwMS routinely use a Health Information File (of some description) as an information source and an aide promoting self-management.
- Professionals providing healthcare advice for people with MS routinely use the Health Information File to ensure that PwMS are reminded of their advice and that other healthcare professionals are aware of it.
- Routine use by PwMS and professionals would reduce the likelihood of the Health Information File being forgotten.

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