

## End of study information sheet- example

### **Experiences of health care for people with MS study 2012-2014**

Dear \_

You recently took part in an interview about your experiences of health care for MS. I am now delighted to be able to tell you the findings from this study. I would be very grateful to hear from you, if you have any thoughts about these findings, and how you would like to see these results used to hopefully improve people with MS' experiences of health care.

These findings come from analysis of interviews with 24 people with MS across the North West, completed between 2012 and 2014 as part of my PhD studies. The people who took part are from a wide range of ages and backgrounds and with different types of MS. Their stories illustrate their experiences of UK health care- both good and bad.

I look forward to hearing any comments you may have, and thank you again for taking part in this research.

Best wishes,

Abi Methley

The University of Manchester

**\*Insert email address here\***

## Study findings

**Figure 1 shows the key patterns resulting from the data, which are explained in more detail below.**

### **1. Experience of living with MS**

People discussed the impact of their symptoms on their daily life and how it felt to live with uncertainty and a lack of knowledge about how their MS would progress. They also discussed living with labels such as *“person with a disability”*, and how these could be positive when they allowed access to services such as blue badges, but negative when they limited peoples’ opportunities. Some people also described what it was like when health care professionals did not believe them about symptoms, leaving them feeling that they were *“neurotic”* or that symptoms were *“all in their head”*, which could have a negative impact on how they saw themselves.

### **2. Managing self-care**

People discussed the variety of ways in which they managed their MS symptoms on a daily basis, without limiting the activities they needed and wanted to do. Some people explained how health care professionals were a big part of this management, whilst others felt that they were *“expert patients”* who had gained experience of their MS through living with it and learning about it over many years.

### **3. Accessing services**

Most people reported the difficulties experienced accessing relevant services quickly, such as during a relapse. Difficulties were also reported accessing community services such as physiotherapy and counselling, and accessing hospital services such as neurology outpatient appointments or contacting MS specialist

nurses. People discussed how difficult it was trying to access and navigate (find their way around) services when they didn't know what was available or who to contact to find out. People described how once they had found this out (often with the help of MS Specialist Nurses or the MS Society) they felt they were "*in the loop*" and knew where to go and who to ask for help. They then tried to stay in the loop through attending regular appointments, in the hope that these would be helpful and offer new information on managing or treating MS. Some people had very positive experiences of their GP or MS specialist nurse helping them to access services, whilst others felt they had to navigate service alone.

#### **4. Interactions with health care professionals**

Although some good interactions with GPs, MS specialist nurses and physiotherapists were reported, many people described their experiences of negative interactions with health care services. These negative experiences were described as having contact with health care professionals who showed poor communication skills, a lack of respect, a lack of specialist knowledge and a lack of knowledge of the individual person with MS. People with MS felt that some professionals made negative judgements about them, and they felt that they were not valued as people but simply seen as "*numbers*".

#### **5. Continuity of care**

Many people in this study described how they felt that their care was not well coordinated, and that health care professionals did not always communicate with each other, or with the person with MS enough. Participants also described the advantages of having a regular GP or MS specialist nurse, and the impact it had on their care when they had to see many different health care professionals. Follow up appointments in hospitals were viewed with mixed feelings; some people felt

like they did not achieve anything or provide anything new, whilst others thought they were valuable as they *“kept a check on you”*.

## Conclusions

Overall these findings report the mixed experiences of people living with MS in the North West of England. People with MS viewed good health care as regularly seeing the same professionals, who they felt they had positive interactions with and experienced care that was well coordinated and easy to access. They also suggest that negative experiences of health care can be due to difficulty accessing services, poor interactions with health care professionals, and where care is poorly coordinated. To improve the care of people with MS, participants suggested that professionals should:

1. Tailor their involvement based on the individual needs and preferences of people with MS
2. Value and listen to an individual’s experiences non-judgementally
3. Continue to improve the accessibility and signposting of services

A key aspect of achieving these aims may be to prioritise the continuity of people’s care, as seeing the same professional regularly may improve the person-centredness of MS care and potentially improve communication.

These findings highlight the wealth of knowledge and experience that people with MS have about their condition and suggest ways to improve services for people with MS.

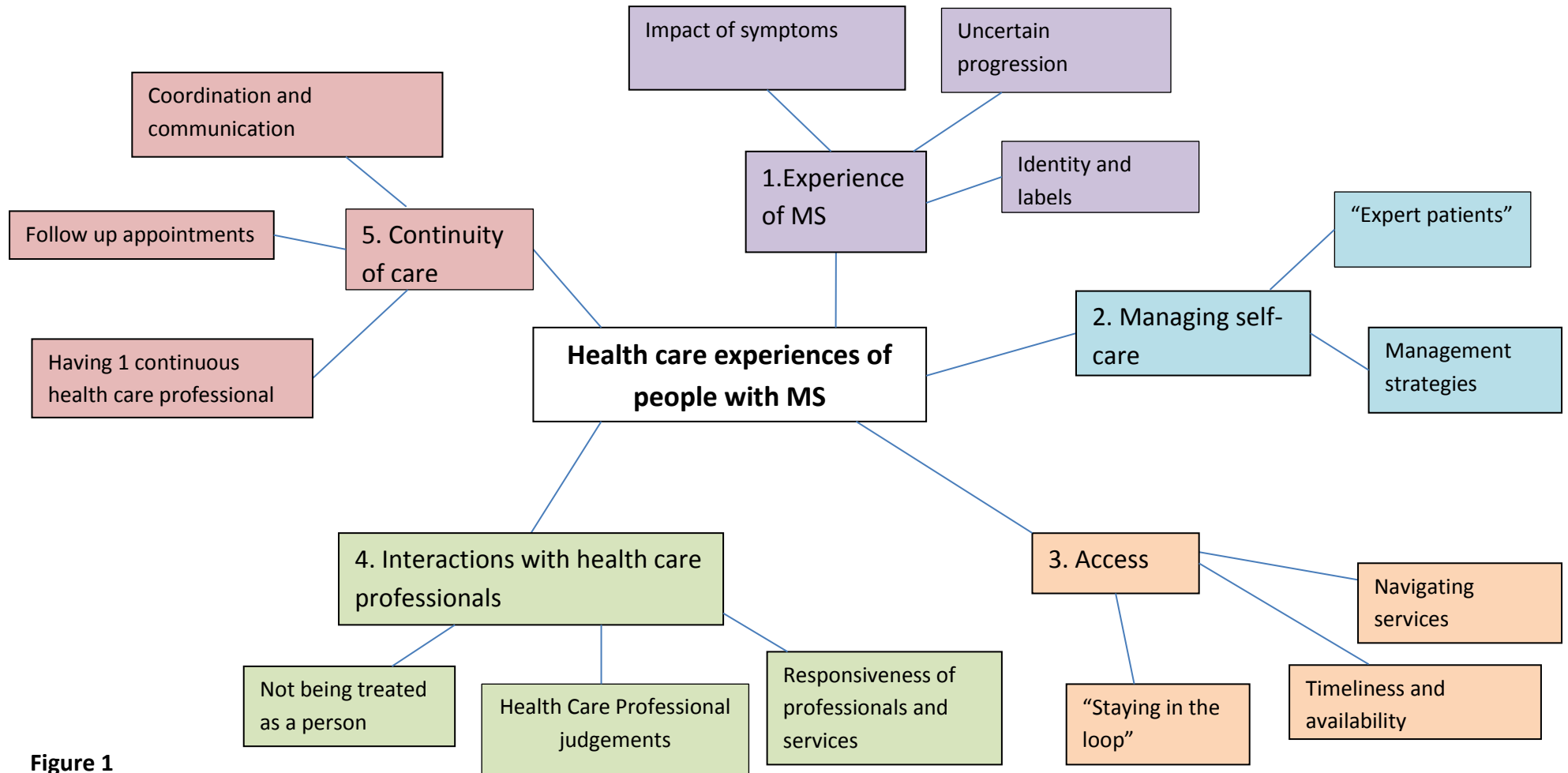


Figure 1

## **How have these results been used?**

1. These findings have already been presented at conferences in Nottingham, Oxford, Edinburgh and New York, to people involved in all areas of health care and health care research, including GPs. They were also presented at one of the largest international MS conferences held recently in Brighton. Delegates at this conference included MS specialist nurses, neurologists and other health professionals from all over the world.
2. These findings are due to be presented at the national MS Nurses meeting in March 2015, which is the biggest annual meeting of its kind in the UK.
3. These findings have been written ready for publication in international scientific journals. This means they will be read, and hopefully used, by health care professionals all over the world.
4. These findings have also been written for publication in the MS Trust Way Ahead magazine, read by many UK health care professionals and people with MS, and will be out in print in 2015.
5. Summaries of these findings have been sent to the MS Society and MS Trust, where they will be distributed to people with MS and carers. It is hoped they will be published in a charity publication in 2015.
6. Summaries of these findings have been sent to major GP and Practice Nurse networks to inform them of people with MS' experiences in primary care.

Thank you for your time and participation in this research, I look forward to hearing any comments you may have.

Best wishes,

Abi Methley

The University of Manchester

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