

# My MS Passport

## Background and Aim

- People living with multiple sclerosis (MS) often find it difficult to keep an up to date record and history of their MS
- Secondary complications resulting from lack of accurate communication can be minimised if an accurate record of care and previous history is documented in a clear and organised format.
- This quality improvement project ran over the past 4 months evaluating the personal clinical and cost effectiveness of a hand held, self-managed personal record for people living with MS.
- It sought to explore the experiences of using a MS Passport perspective of both the person with MS and people that are involved with their care.

## Methods

- Participants were selected to share their experiences of using a MS Passport throughout the 16 weeks of the study.
- They were asked to provide feedback, if possible during or after each time they attended appointments to record reflections on how it felt when using their MS Passport, changes they were experiencing, and any other comments they wished to make.
- Participants were not given a detailed guide of what to record so as not to direct responses.
- Recordings were logged



## Results

- Twenty three participants (with MS 12 female and 8 male, aged 24 – 71 years) and three professionals recorded their experiences.
- Analysis resulted in the emergence of four themes described here and supported by anonymised participant quotes:

### "Noticing a difference"

The variety of changes people reported in their experience at appointments as well as wide ranging symptoms such as confidence, mood, self management and empowerment are captured in the Feedback below.

"A great aid to help keep me organised it is really helpful to have everything together in the one place"

"It is amazing to feel prepared and I am beginning to realise that this is my condition"

"I feel much more confident going to my appointments. Especially if I am asked to give a history."

### "Feeling like the old me"

A sense of normality gained from utilising the MS Passport, and the physical, psychological and social benefits experienced. - demonstrated by the following participant quote:

"I don't look at the MS Passport as a weakness it is just like the keep fit journal my sister uses."

### "Getting Organised"

People reflected the value placed on having guidance and support in establishing a comprehensive hand held document; including the importance of initial support and discussing issues such as initial population of information care plans etc thus enable them to build a comprehensive log and any address any other issues associated with starting to use their MS Passport'

"Best thing that could ever have happened for me as I have short term memory problems"

"As I have everything to hand It enables me to map my progress. It takes a lot of the pressure away that I previously had me when attending the GP everything is clear in my care plan and my relapse pathway is there for me to share with any professional and"

### "Will I be able to do this?"

This highlights the issues faced by people living with a progressive and fluctuating condition in implementing the Ms Passport. Many participants talked about how the unpredictability of their condition affected their ongoing ability to recall and document events, and that this could change on a day-by-day basis.

"To begin with I felt That this was just another paper exercise and was very sceptical I felt it would be hard work the whole time... Initially over the first few weeks it was and now that it has been populated I have a very comprehensive MS Passport with all the relevant information that I need.... it really has given me a sense of control and confidence back in my life. It also has taken away a lot of the fear of the future And helping me to focus on the here and now"

## Conclusions

- Use of the MS Passport has given people a personal hand held document to take to all their appointments and admissions to hospital. This has evidenced empowerment and incorporated regular self-management into their journey with MS .
- Associated with the use of the MS passport it was reported that it had encouraged a wide-range of physical, psychological and social benefits.
- It is important to consider Provision of initial and ongoing guidance and support and regular reviews with programmes of this nature.
- NHS Western Isles are looking to utilise this documentation for all long term conditions and are developing and app version in conjunction with M Power.