

# Proactive considerations towards employment commitments when receiving a Disease Modifying Treatment for Multiple Sclerosis: Employment Leaflet for Lemtrada Therapy

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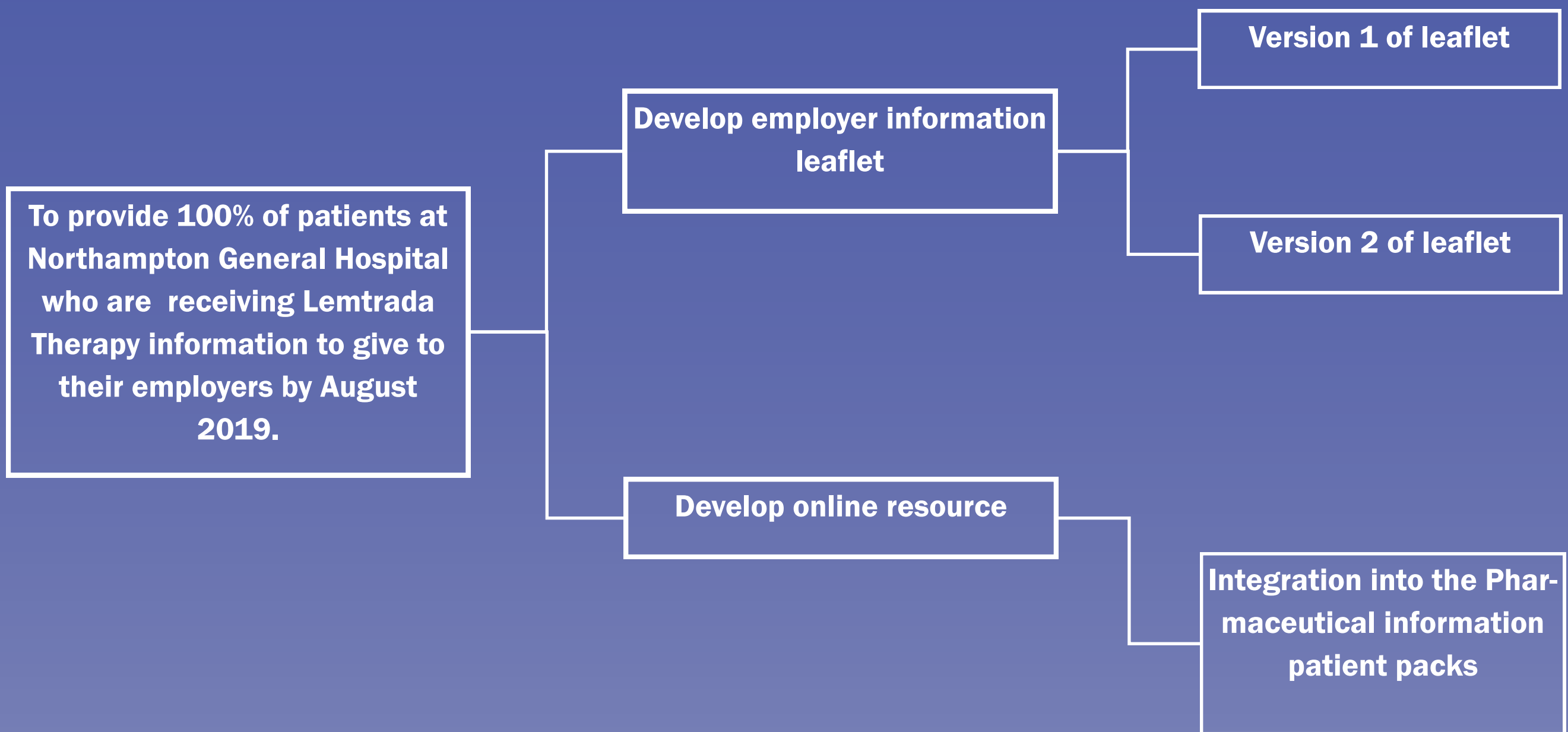
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## Background

Many people with Multiple Sclerosis find it hard to spark a conversation with their employer about a diagnosis of MS (Multiple Sclerosis) due to fears including discrimination, misunderstanding and misconceptions. Although there are various trusted resources of information provided by such sources as the MS Trust and MS Society, there is nothing specific with regards to Disease Modifying Treatments and its impacts that this may have with regards to time off work and support on return. A recent survey from the MS Society (2016) observed that only 55% of people with MS are in work compared with 75% of the general population. For 44% of people with MS of working age that are currently employed feel that they need much more support to continue to work (MS Society 2016 Exploring employment support needs – employment and welfare analysis of My MS Needs). Disease Modifying Therapy are useful in stabilising and maintaining MS longer term, however also impact on this ‘normality’ in the shorter term too. Unemployment has many negative consequences including financial, social, economic and personal high cost and burden. It was identified that more proactive considerations were required for future patients considering LEMTRADA to enhance communication with employers and seek support, understanding and commitment for this treatment option. – investing in a sustained future workforce.

## What are we trying to accomplish?



## What change can we make that will result in an improvement?

### PDSA 1

The first PDSA cycle was to develop a patient information leaflet that could be given to patients during their consultations. This facilitated discussions, with the patients, about their employment and aided them to have further conversations with their employers.



### PDSA 2

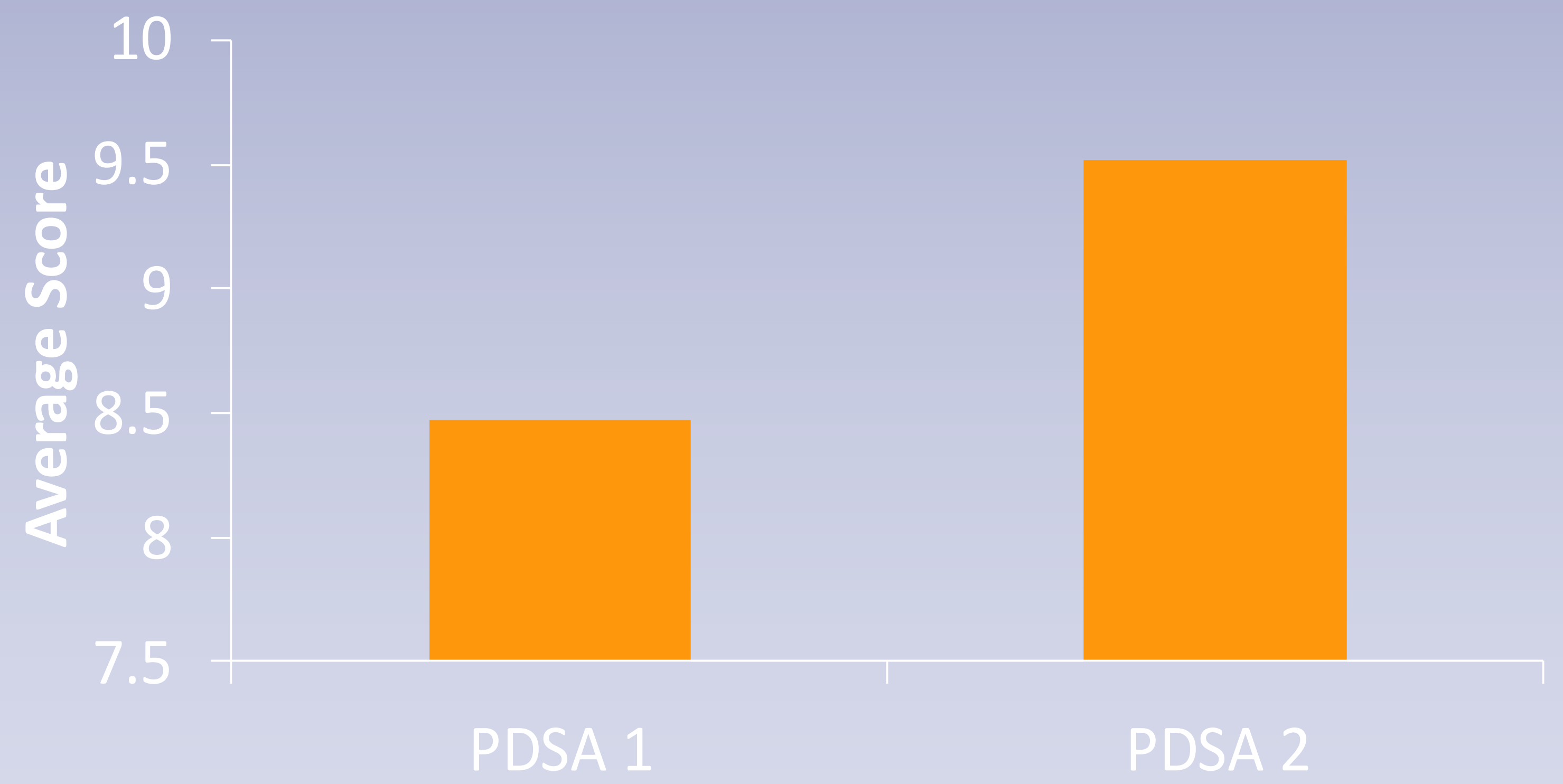
The second PDSA cycle involved redeveloping the leaflet following feedback from patients and their employers

## How will we know that a change is an improvement?

**Outcome Measure:** 100% of patients commencing on Lemtrada Therapy now receive this patient information leaflet containing information to give to employers.

**Balancing Measure:** It was important the information could be easily understood by patients and their employers so we surveyed employers to gain their feedback.

Average score out of 10 on how easy the leaflet was to understand by employers



**Qualitative Measures:** When surveyed following the implementation of the leaflet patients responded with really positive comments including:

- ☺ I love it!
- ☺ Really useful and informative
- ☺ I really like how succinct the information is
- ☺ The list of side effects with pictures is useful and extremely accurate!

## Further Planned PDSA cycles

Further PDSA cycles are planned to further enhance the information patients receive. They are being surveyed to find out what areas of their treatment/disease they would like further information on.

Planned PDSA 3—Develop online tool

Planned PDSA 4— Further leaflets for disease modifying therapy

## Conclusion & What's Next?

For patients receiving Lemtrada therapy the value of maintaining a work/life balance is extremely important for many aspects of a persons lifestyle and quality of care. It is important to preserve a positive experience and ‘normality’ where possible to promote concordance to treatment. Maintaining employment throughout treatment has been seen to improve mental health, self-worth and motivation this then enhances independence, financial stability and societal status. As a result of the leaflet, conversations with people with MS and their employer can start early in the treatment process to limit its impact and gain the required support.

**Next Steps:** It is anticipated that the leaflet will be integrated into the Pharmaceutical Information patient packs and be available as an online resource on the patient portal. The development of a series of leaflets for disease modifying therapy is now in progress.

