

Patient feedback survey on the Subcutaneous Injection (SC) for Natalizumab (Tysabri) Service at Wessex Neurological Centre Report

Introduction

A new way of taking Tysabri (natalizumab) has been approved for the UK and Ireland in 2021. The MHRA (Medicines and Healthcare products Regulatory Agency) and European Commission have granted marketing authorisation for an under-the-skin (subcutaneous) injection of Tysabri. (MS Trust 2021)

At UHS, it can take a couple of hours to have a Tysabri infusion and some people have to travel a long distance to get to their infusion clinic. Subcutaneous injections will take less time than the infusion. Clinical trials have shown that monthly subcutaneous injections of Tysabri are as effective as monthly infusions at reducing relapses and lesions seen on MRI scans. About 7% of people (less than 1 in 10) experienced mild or moderate injection site reactions when having a subcutaneous injection of Tysabri.

Objective

The MS team at UHS has introduced the new formulation of Tysabri in August 2021. A letter was handed out to each patient 1-2 months ahead outlining the new formulation and offering patients information and a chance to discuss with their MS team (MS nurse and or consultant) switching when the drug becomes available.

The objective of the survey is to gather patient feedback on the new formulation of SC natalizumab since the service has started for the last 6 months. To understand what factors affected the patient's choice in switching and how we can learn as a service to improve patient care

Comment
The team are really friendly and have allowed me to overcome my fear of needles
Feel comfortable, we are friendly.
Everyone is friendly and welcoming
Everyone's polite, and they try their hardest
Excellent service, ms nurses knowledgeable, nothing to improve
You are a lovely team. Over the past few years there have been so many changes in the team some which were absolutely devastating. I'm always pleased to see you. You always make me feel welcome. Keep going, you are doing a great job!
I find the injections much better, easier, and don't have to be cannulated which is a good change after 8 years on tysabri! I only wish I could have the injections on the Isle of Wight as challenging to Southampton can be expensive. But the nurses at Victoria house are fantastic and I've loved switching over. Thank you for everything and for making it an easy process.
Nurses are brilliant
Very friendly manner
I find the injection painful
Tysabri Tuesday fabulous service and nurses Could not ask for a better team
Great care, infusion process is quick and easy
It's very quick and easy
Friendly and supportive staff
MS nurses are fantastic, friendly to talk to and will listen and advise to any questions or updates I have.
No side effects that's good, I'm not good with needles, my veins collapsing from time to time
Nurses are very kind and helpful
Very friendly staff, always comfortable & straightforward
Simple, painless, shorter time to stay in the hospital
Staff are always pleasant, super helpful, very knowledgeable and understanding. I enjoy going and relaxing/chatting to the nurses while they do the infusion 😊
The infusion service has been amazing to me. I have had reactions to 4 Tysabri infusions out of 5 and the care I received was phenomenal. I was treated with care and dignity and welcomed back with affection despite knowing I was likely to have another reaction. Couple that with having rubbish veins and great patience, I can't speak highly enough of the care I received. I have now moved on to the injection which having have one course without issue I am hoping I will now get to just enjoy the more social side of the infusion centre.
It's not been 100% perfect, had a relapse when they tried to extend the time during lockdown, also been positive to the bad illness. Sorry brain fog with exact name.
Friendly nurses who put mind at ease
Always very professional and friendly, always willing to listen to the patient.
Infusion staff are wonderful. Couldn't ask for better care.
Smooth & quick. It will be even speedier when I have a shortened observation time in 2 months time!
The team are always welcoming and friendly and put me at ease. Making me feel confident that I can do it 😊
Nurses are very friendly and knowledgeable of MS thus able to answer questions or advise if there is a problem
The staff are superb. They are knowledgeable and put you at ease.
The MS infusion nurses we're very informative and caring. Nothing better could have been done.
The nurses are great! Every time I go they are always smiling (you can still tell even with all the PPE on) they are very friendly and reassuring.
Very efficient and caring service
YOU'RE PERFECT

Results

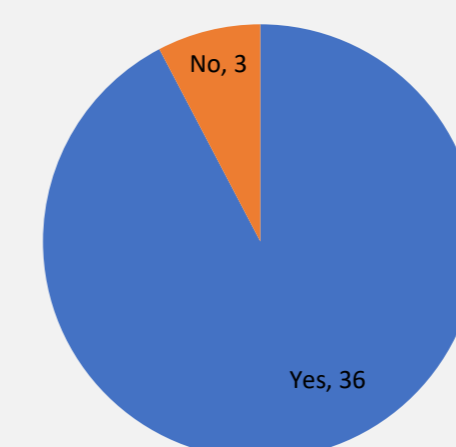
Most respondents were female (42), males (12)

Age- between 35-54

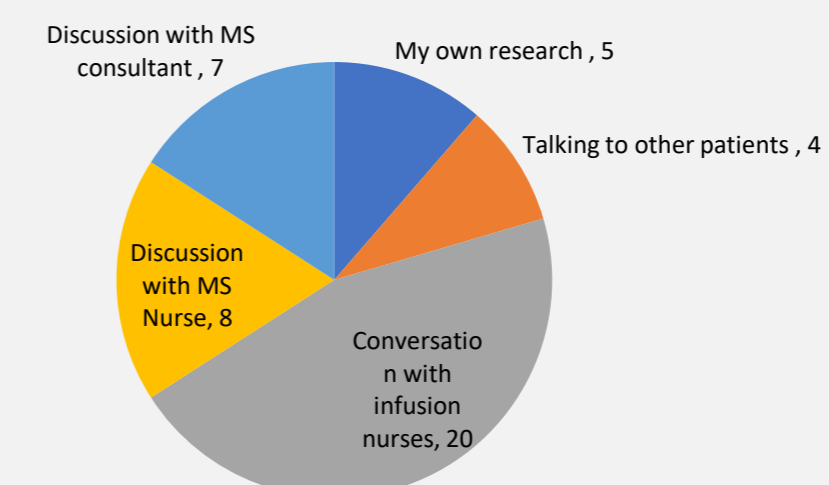
When did you start SC injections of Tysabri? **If you haven't started SC injections, why is this?**



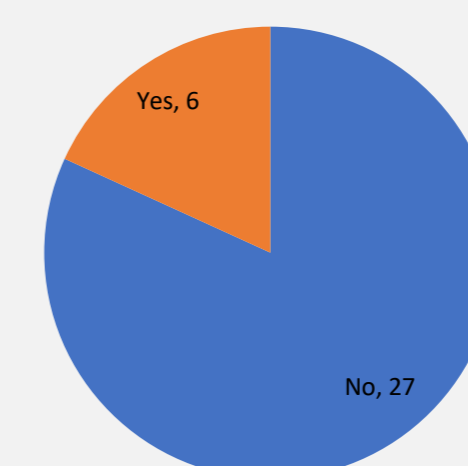
Was there sufficient communication prior to starting SC injections?



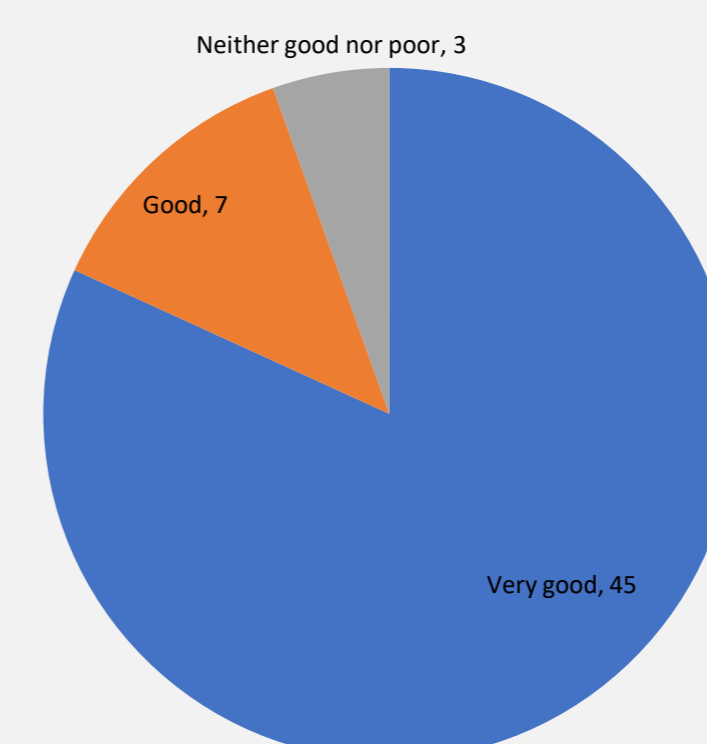
What prompted you to change from Intravenous to subcutaneous injection? Please select all that apply



Did you experience any reaction post injection?



Overall, how was your experience of the infusion service?



Conclusions

It has been a very positive feedback from our patients. The service even tough with all the challenges in the last 2 years, have managed to deliver a very good experience, especially with the new formulation of Tysabri.

Communication was the notable factor in this feedback both before, during and after the transition to the new formulation. The conversation with the infusion nurses was the biggest factor in delivering this service. More and more patients are switching as confidence has increased this last few months. The authors would recommend looking at the clinical aspect of the patient's journey and collating MRI results for all patients who have switched to SC for over a year.

As of March 2022, we have 87 patients on IV Tysabri and 79 on SC Tysabri. New starters are always started on the IV formulation unless otherwise discussed at MDT. We currently have 8 patients who chose to switch back to IV due to several factors (return of symptoms, 'treatment lag', dizziness, fatigue, headache and painful injections. These symptoms are poorly understood currently and will require further review and investigation.

References

- MS Trust (2021)