

# Alemtuzumab Patient Satisfaction Survey

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**BACKGROUND:** Alemtuzumab is a monoclonal antibody treatment for relapsing remitting multiple sclerosis (RRMS). This treatment has only been used in the UK for RRMS since 2014. The Wessex Neurological Centre (WNC) which looks after a population of over 4,000 MS patients (NHIS 2016) started this treatment in 2015. The Wessex MS team has infused over 100 patients. We wanted to gather feedback from patients on how the service is providing this care both logistically and practically and to suggest how we can improve things for a better service.

**AIM OF THE POSTER:** To share our experiences in providing the Alemtuzumab service to other centres in the UK.

**WHY THIS WORK IS IMPORTANT:** Any new service should be evaluated by gathering patient feedback in order to improve. Patients are the service users and their input in improving any service is paramount in maintaining patient safety and experience.

**WHAT WAS DONE?:** A Survey was written and sent to patients considering the whole pathway from treatment proposal to monitoring. The survey was reviewed and approved by the hospital's Patient's Experience Group. Patients were given three weeks to return this. The results were collated and presented to the Wessex Neuro staff, management team and wider MS Wessex Team.

**SUMMARY & KEY POINTS:**

- Generally feedback was very good (giving staff delivering the pathway encouragement and satisfaction)
- Some delays in pre assessment and communication have now been addressed
- Most problems were reported with inpatient stays. Therefore patients only stay as inpatients if medically required. They are no longer given the option of inpatient v daycase.
- Monitoring can be a problem for some patients. A digital patient portal is being developed with the Trust. Patients are given access to a team email.
- Introduction of phlebotomy service has made a difference in monitoring.
- Introduction of a Virtual clinic to reduce amount of hospital out patient visits.
- Considering changing some of the pre medication to reduce commonly reported side effects

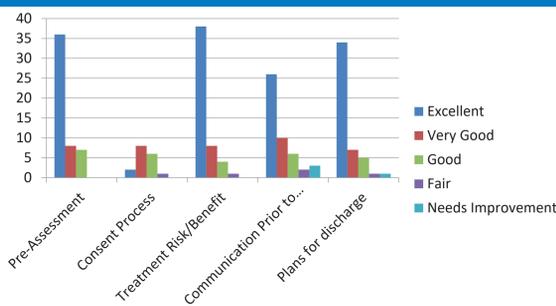
## Day Case vs. In Patient Admission

Day case	InPatient
87 patients (66%)	45 (34%)
11 patients received 2nd cycle as day case and 1st cycle as In patient	Rationale for In patient stay: Geography/ distance: 21 Patient request: 12 New Service: 4 Medical Reason: 8 Recent Relapse: 3 Co-morbidities or Symptoms of MS: 5
** 1 day case patient admitted due to vasovagal attack following numerous failed cannulations	

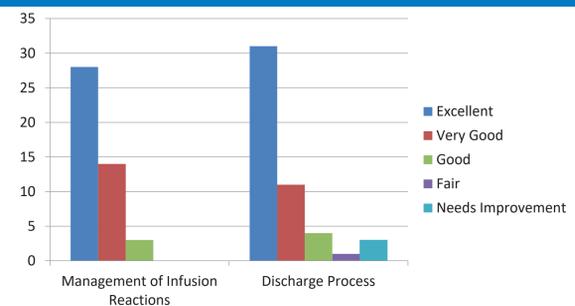
## Patient Survey

Number of Survey sent out to	115 patients
Responders	52 (45 % response rate)
Daycase	37 (71%)
In Patient	15 (29%)

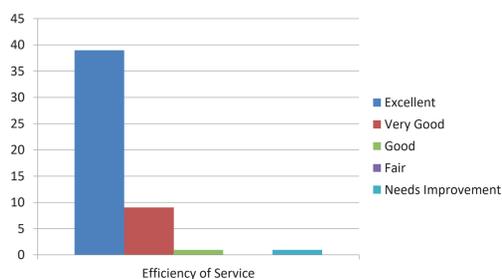
### Prior to your infusion



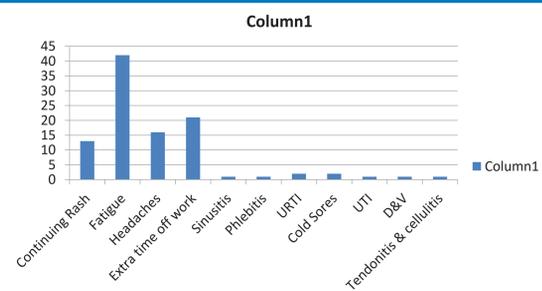
### Both Admission



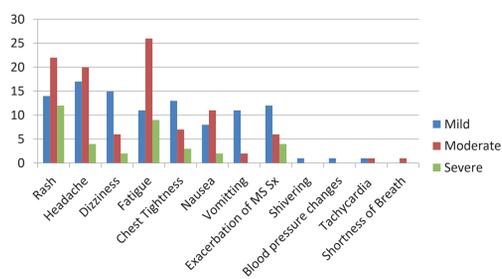
### Infusion Experience



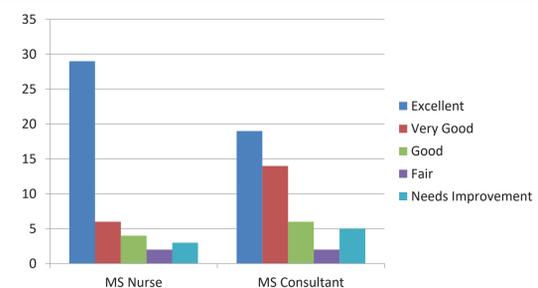
### Significant events 1st 2 months post infusion



### Infusion Reactions



### Follow-Up Care



## Patient Comments

### Things that went well

- "Nurses were amazing and made me feel totally at ease and informed me of what to expect"
- "Being able to directly contact the MS nurses takes a massive weight off my mind, their support is not only appreciated by me. But I am sure the GPs too when I've been advised to visit"
- "All of my infusion reactions were spotted early and treated extremely quickly by the nurses"
- "Being able to be an inpatient was appreciated especially with regards to managing the reactions. I'm not sure I would have coped at home"
- "Back on phased return after 3 weeks sick leave. All planned and discussed with nurses and work"

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### Things to improve

- "Advise patients to bring a fleece blanket and wear jogging bottoms. It's hard to handle buttons, zips etc with a cannula and drip stand attached."
- "The last time I have seen an MS Consultant was November 2016. My next appointment won't be until October 2018 due to cancellations"
- "The discharge process was not very good as finished the treatment around 3pm but did not get discharged until 9pm as we were waiting for prescriptions to take home and still at 9pm they couldn't give me my full prescription, only half and had to pick up rest from my GP"
- "It's very difficult to get a bloods appointment when I can't make the hospital. I had no follow up for MRI or smear. I'll need to contact the specialist nurse and prompt her"