

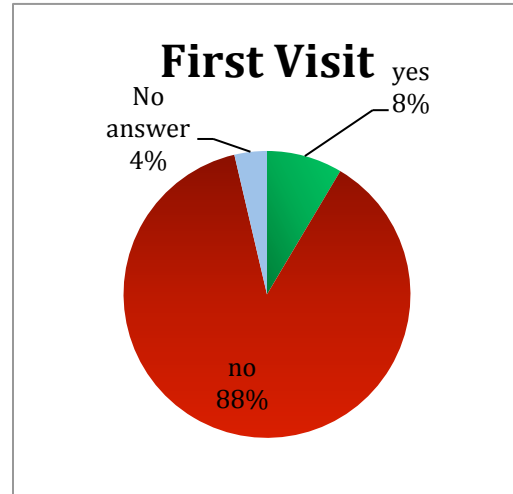
Appendix 3

National Aspergillosis Centre patients survey

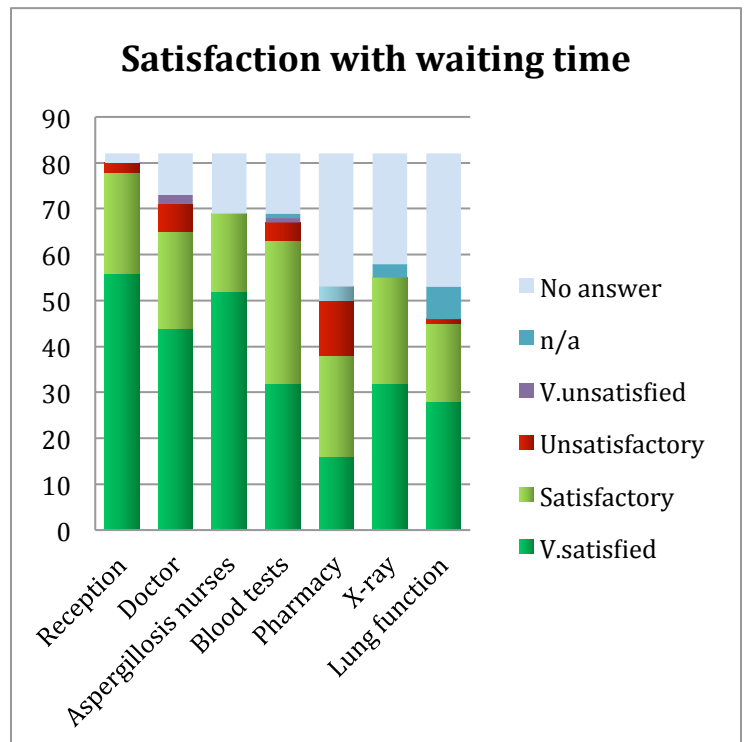
The survey was issued to all Friday clinics in January-February 2013 of which a total of 82 patients returned the survey.

CPA Clinic

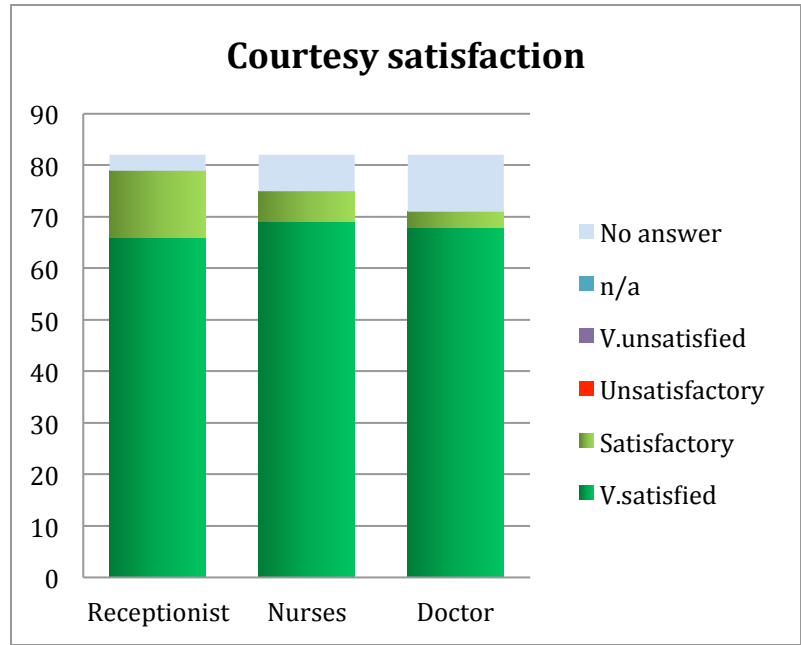
1. 82 patients completed this questionnaire. 88% of these patients have already been before and for 8% it is their first visit. 18% of patients have noted their condition with it predominately being CPA.



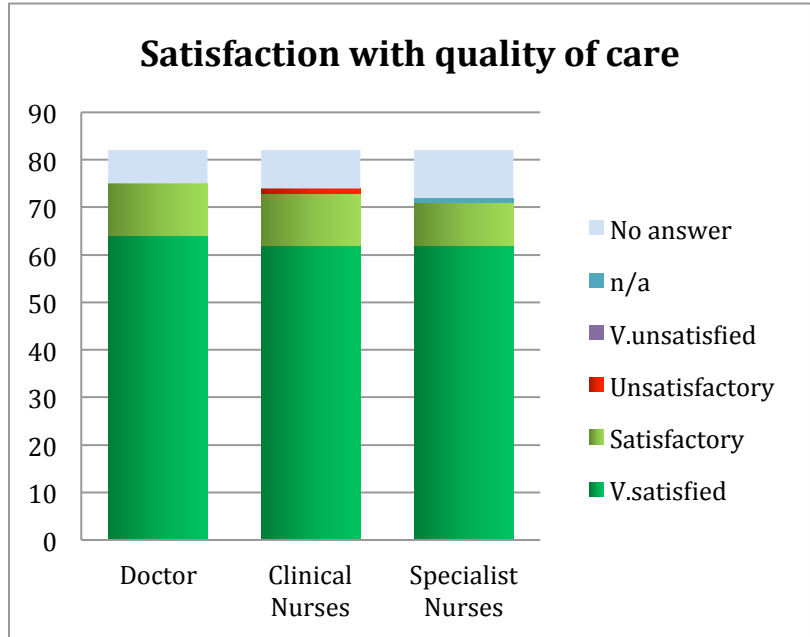
2. Patients are mostly happy with the waiting time for reception and aspergillosis nurses with patients feeling very satisfied in 68.3% and 63.4% respectively. The waiting time for the pharmacy has the least people finding satisfactory/very satisfying with 46.3%. The number of patients not answering the questions increases as you move across the x axis but it is unclear why this would be other than patients not using those services.



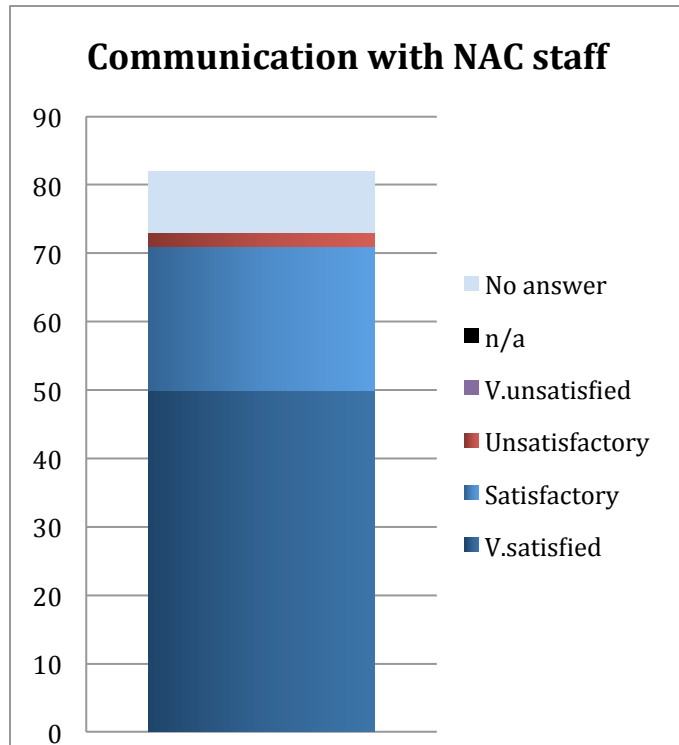
3. No patient found the courtesies they received to be unsatisfactory with a minimum of 80.5% of patients being very satisfied with receptionist, nurses and doctors.



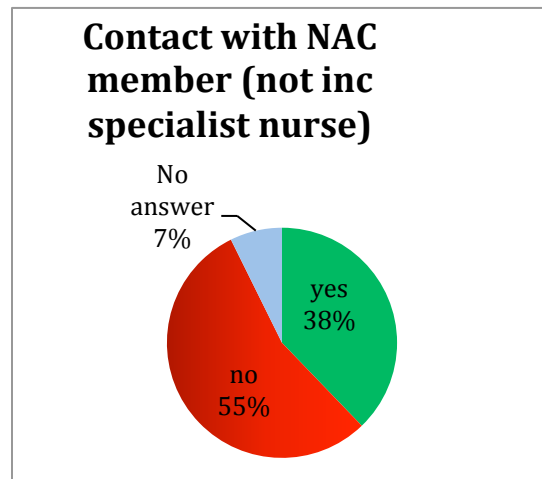
4. 75.6% of patients were very satisfied with the quality of care. The rest that answered found it satisfactory except one patient found the care of the clinical nurse to be unsatisfactory.



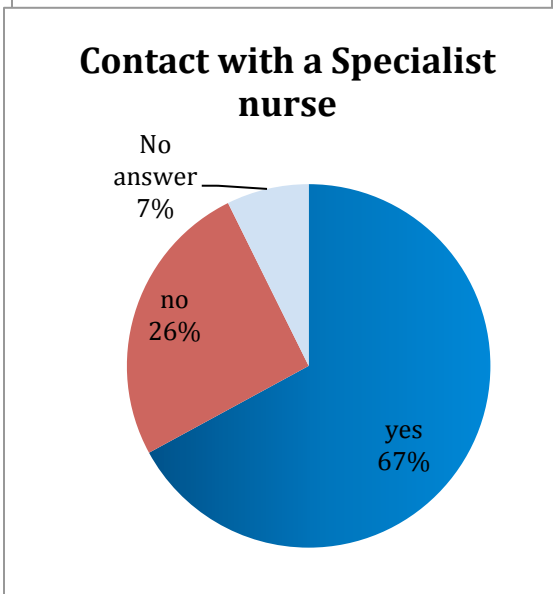
5. 68.5% and 28.8% of patients who answered were very satisfied or satisfied respectively with the communication with the NAC staff. 2.3% of those who answered found the communication with NAC staff to be unsatisfactory.



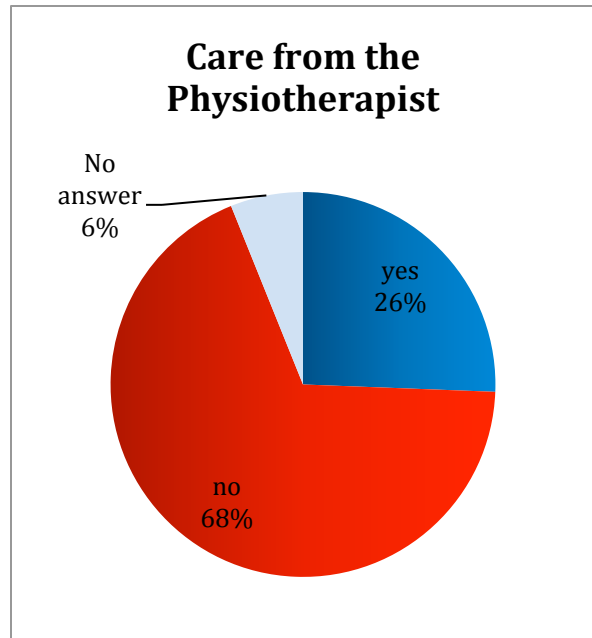
6. 38% of patients had contact with a NAC member after or between visits. However, as with all the other clinics, there is mass confusion in answering this question. Many have put the names of specialist nurses which strongly suggests that the patients are not reading the question correctly.



7. The chart shows that 67% of patients had contact with a specialist nurse in-between visits. 89% of these patients who were contacted were very satisfied with the support and the remaining 11% found it to be satisfactory. There were several compliments towards the nurses for being so helpful and supportive.

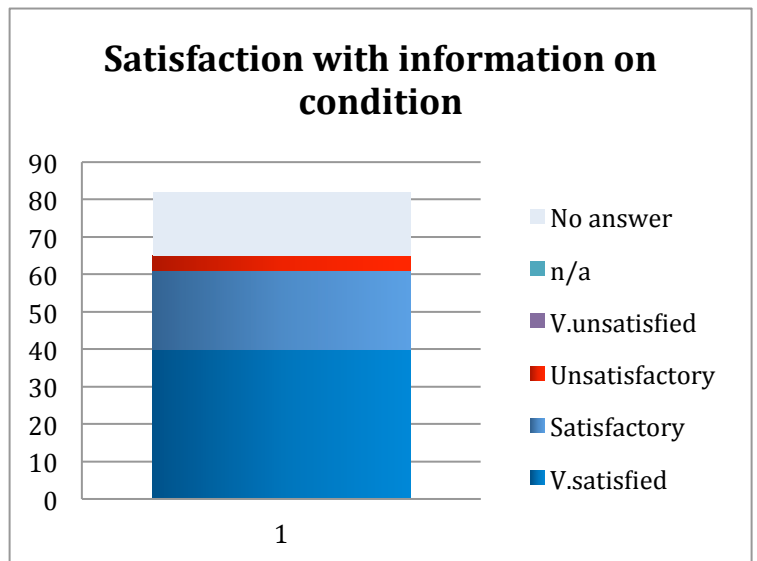


8. 26% of the patients have received care from the specialist physiotherapist with 87% of these being very satisfied with the service and the remaining 13% finding it satisfactory.

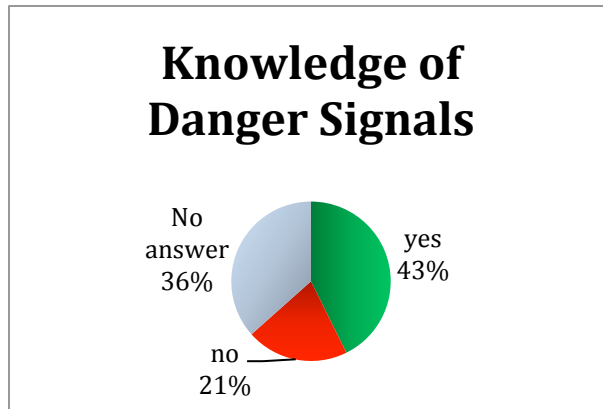


9. 5% of patients had seen the consultant immunologist, all of whom found the service provided a very good explanation when questions were asked. The other 95% of patients made no comment on if they saw the immunologist or not

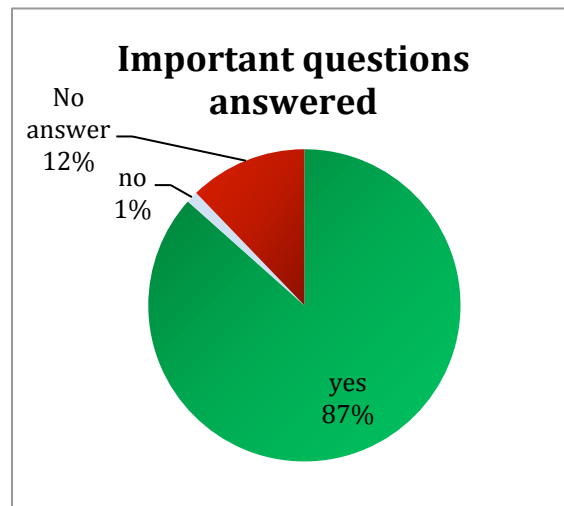
10. 93.8% of patients who answered were either satisfied or very satisfied with the information they received on their condition. 6.2% of those who answered found it unsatisfactory but with do not give a reason to why this is the case.



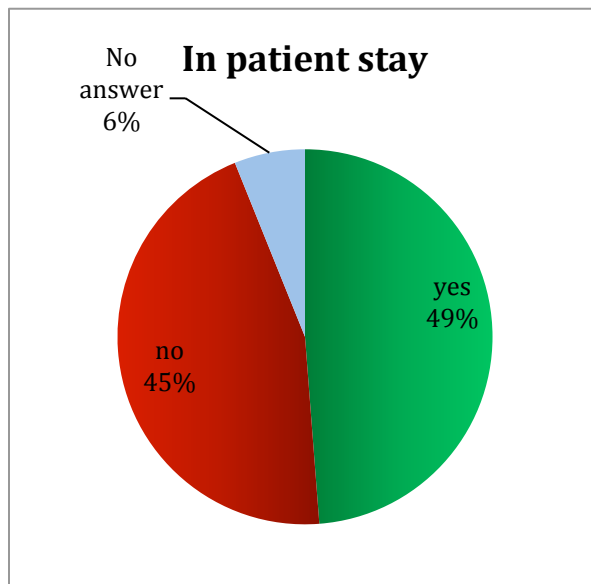
11. As shown, 43% of patients were told about the danger signals regarding their illness. 21% said they were not told of the danger signals. It is unclear why such a large proportion did not answer this question.



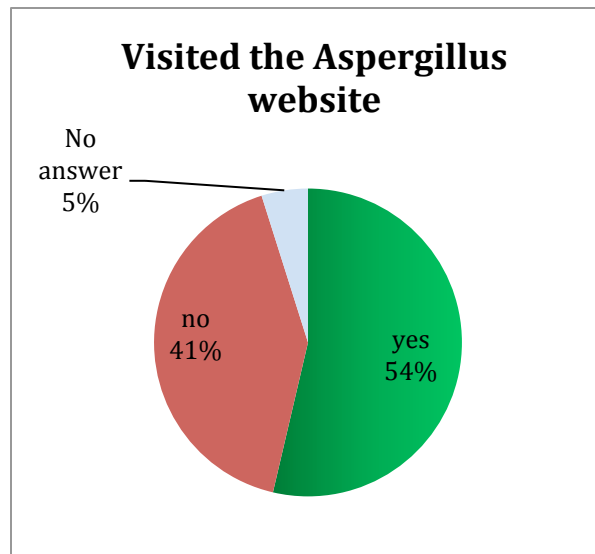
12. 87% of patients had their important questions answered with only 1 patient questionnaire answering no (1%).



13. Approximately half of patients had had a patents stay in Wythenshawe hospital. Of these, 5% felt they were not treated with respect and dignitiy whilst in hospital.

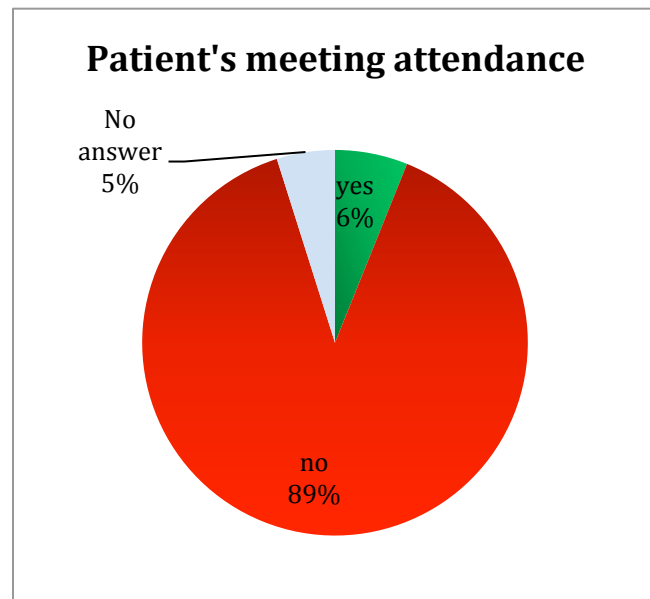


14. 54% of patients had visited the Aspergillus website. These patients were satisfied or very satisfied with the site except 1 patient out of the 82 questionnaires, who was very unsatisfied with it. No explanation to why was given. Of those that answered no, 32% of them do not have a computer or use the internet.



15. No patient stated if they wanted more information other than what was already available with most patients choosing not to write anything for this question.

16. 89% of the patients at the clinic have not attended the patient's meeting or did not answer the question.

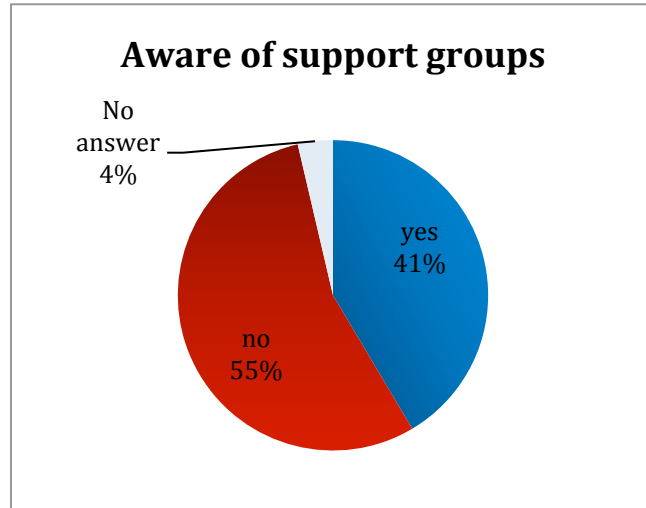


Of those that said no, and of those that gave reasons why, 66% found the time or place of the meeting to be inconvenient. 5.4% of patients said that they thought that the meetings didn't sound useful for their needs. 28.6% of patients said they didn't feel they needed the extra support and/or were happy the way they were. Please note that this

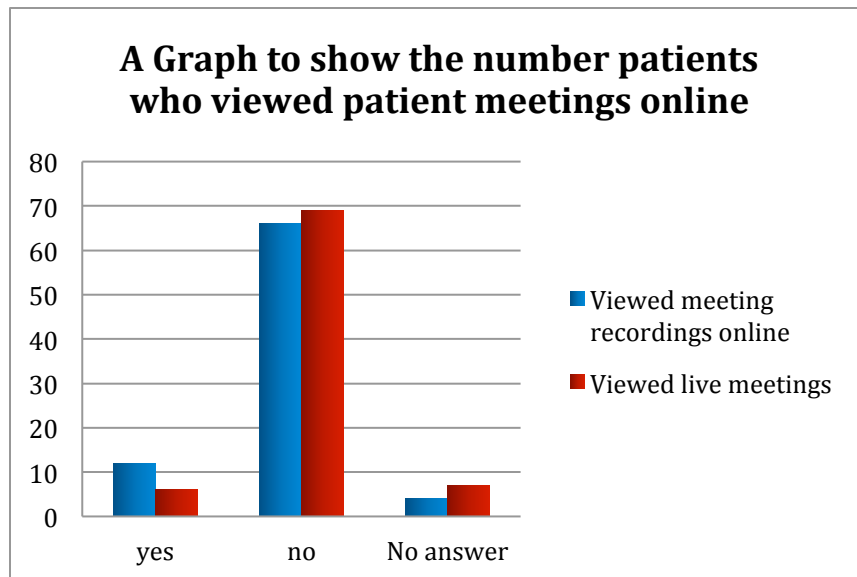


graph includes the results where some patients have put multiple reasons for why they haven't attended.

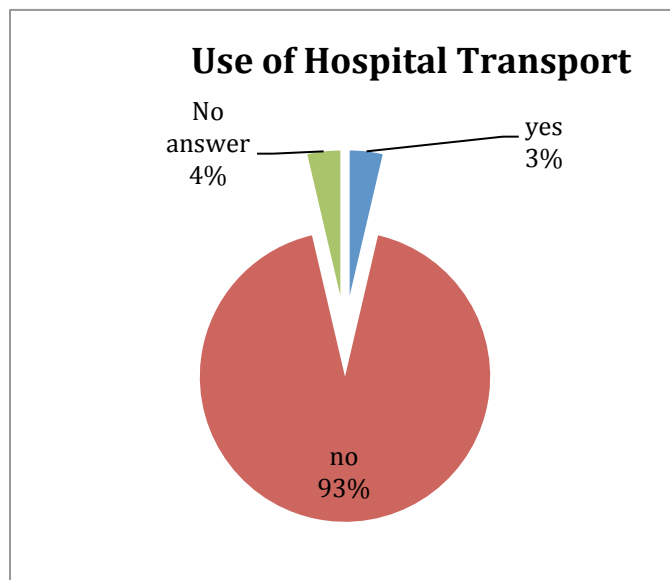
17. 41% of patients are aware of the patient led support groups around the UK. None of these had made contact with a group. 1% of patients wanted information about setting up a group in their area (no postcode was given).



18, 19. 14.6% of patients viewed the patient meetings online recordings and 7% viewed them live on the internet. Over 80% do not view the meetings either by watching the recordings or online.



20. 93% of patients do not use hospital transport. The 3% that do are mainly satisfied or very satisfied with the service with one patient finding the service unsatisfactory. The two patients who used public transport and who gave their postcode were travelling from Oldham.



20. 83% of patients are happy to be part of clinical research. All except one patient, who had already been part of clinical research, was satisfied or very satisfied with the procedures and consent process. The one patient that answer that is was unsatisfactory was because they were at the hospital for over 3 hours.



Appendix 4Publications from the Manchester Fungal Diseases Group (2012)

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