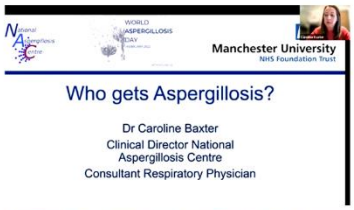
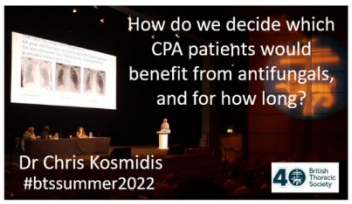
NHS National Commissioning Group - Highly Specialised Services

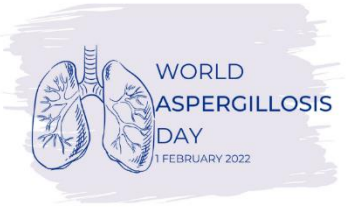
Chronic Pulmonary Aspergillosis National Service

The National Aspergillosis Centre

Annual Report 2021-2022







Contents

Appendices

1. Annual Service Overview and Highlights

This report covers the fourteenth full year of the National Aspergillosis Centre (NAC), commissioned by NHS England as a Highly Specialised Service for the treatment of Chronic Pulmonary Aspergillosis.

This year has continued to bring new challenges due to the Covid-19 (SARS-CoV-2) global pandemic. The way we run our service has changed remarkably bringing about great benefits for many but times of uncertainly and frustration for others. We have had to embrace changes and ensure they are able to deliver continued excellence in patient care and experience. Our team has continued to show remarkable teamwork adaptability, and innovation throughout the year.

A total of 49 new patients from England and Scotland (plus a further 3 patients from Wales and 1 from Northern Ireland) were assessed at the NAC and diagnosed with Chronic Pulmonary Aspergillosis (CPA) between 1st April 2021 and 31st March 2022. This was out of a total of 184 new patients referred and assessed for all forms of Aspergillosis. Referral numbers have begun to pick up during this second year of the pandemic as patients have started to be seen more frequently in primary and secondary care. We have observed a steady number of patient deaths within the service as a whole and also for new patients within the first year of referral. We have not seen excess deaths due to acquisition of Covid-19 infection, although the majority of our patient cohort have taken up the vaccination programme having been deemed high-risk. There has been a continued increase in discharges from the service due to robust MDT discussions of patients with stable disease, not on current antifungal therapy. Many of these patients are discharged from the commissioned service but remain under our care in the tertiary MFT Aspergillosis service. At the end of March 2022, we had 304 patients from England and Scotland on service and a further 16 patients from Northern Ireland, Wales, The Isle of Man and overseas (non-commissioned funding).

Waiting times for new patient appointments have remained low, under 5 weeks. We have maintained our out-patient follow up activity using an evolving hybrid of video consultations, telephone consultations and face to face appointments. The number of face-to-face appointments has gradually increased but is still primarily utilised for patients who are unwell or require a change to treatment/monitoring. Hospital admissions have also increased this year but remain low compared to pre-pandemic years. Our elective surgical procedures and embolisations have recovered to pre-pandemic levels. Our OPAT service has remained active, but we have also been able to deliver OPAT services to patients via their local teams while remaining under our close observation and expertise. Overall drug expenditure has reduced which reflects Posaconazole coming off patent. The rate and proportion of the different antifungals prescribed has remained stable, when excluding 2020 due to the pandemic.

We continue to monitor our patient outcomes carefully. Within the first year of treatment, in 2021-22, 50% of patients showed clear clinical improvement, 22% were stable, 5% showed deterioration (but had a new treatment strategy put in place) and 23% died of comorbid conditions. We gave a total of 42 new antifungal drug trials. Our trial data showed a 60% success rate,19% adverse drug reaction rate (therapy changed), 17% death rate and 4% drug trial failure.

There have been no serious untoward incidents, formal complaints, or incidents. We have a clear governance structure and mortality review process. Feedback from both our new text survey and the annual patient survey continues to demonstrate high rates of satisfaction.

Patient support has never been more important than during the global pandemic. Our CARES team (Community, Awareness, Research, Education, Support) have been there to support our patients throughout this very difficult period. The year 2021 – 2022 has seen some moderation of the impact that the COVID-19 pandemic has had on NAC patients compared with 2020-2021 but nonetheless there have continued to be several areas of concern for patients with multiple variants of the virus, continued restrictions to 'normal life', several vaccinations and continuing limitations to how all of NAC can communicate with patients. We have again had to be pragmatic and adaptable to best support NAC patients and carers. The team have provided support to patients via several platforms including telegram group communication, monthly Zoom educational meetings, weekly social support Zoom meetings, health and wellbeing meetings and our quarterly newsletter. We have seen a significant increase in activity through our social media channels with a >30% increase in activity across Facebook, Twitter and LinkedIn. We additionally have taken a new focus on our patient and carers website which has seen a large rise in usage. Over the coming year the team will focus on supporting patients through the introduction of MyMFT, an integral part of our Trust's new electronic patient record 'Hive' powered by Epic. MyMFT will be the patient portal which will give patients access to their own health records, appointments, and telehealth. We have continued to raise public awareness and educational outreach via World Aspergillosis Day 2022, social media, attending international conferences, clinician education throughout the UK and the development of a new MIMS primary care module.

The NHS Mycology Reference Centre Manchester (MRCM) provides the high-level diagnostic mycology service for the NAC and has successfully retained its UKAS accreditation in December 2021. The MRCM has additionally renewed its European Confederation of Medical Mycology centre of excellence diamond award. The laboratory is the largest mycology laboratory in Europe with a strong performance in turnaround time, critical results reporting in 1-hour, clinical audits, publications, and international representation. The mycology laboratory has seen a 33% increase in activity over that last year necessitating an increase in staffing levels The MRCM has been at the forefront of diagnostic developments for Aspergillosis in the last decade, with pyrosequencing to determine azole resistance, high volume fungal sputum culture and Aspergillus IgG determination by lateral flow assay. The MRCM is pivotal in new drug development studies and susceptibility testing.

The NAC has continued its reputation in international research with 14 publications relating to aspergillosis diagnostics and treatment. The team delivers educational lectures and seminars nationally and internationally.

Our primary aims for the forthcoming year include building our remote national MDT and partnerships with other hospital teams that are providing local fungal services, increasing awareness of our service nationally and picking up the service re-specification work as guided by NHSE. Above all, our greatest project and challenge will be in supporting our staff and patients through the introduction of Hive and MyMFT.

2. Clinical Service

2.1 Clinical Service Overview

The NAC is commissioned by NHSE to provide care for patients with Chronic Pulmonary Aspergillosis (CPA) – this includes initial assessment and diagnosis, evaluation of disease status (banding), prescription of antifungals, and ongoing long-term clinical management. Referrals are from specialist hospital consultants, predominantly in respiratory medicine and infectious diseases. We aim to see patients within 6 weeks of referral. The service has adapted its delivery of care during the Covid-19 pandemic in accordance with government policies and patient choices.

We have adapted our clinic lists to include a mixture of face-to-face appointments, video consultations (Attend Anywhere) and telephone appointments. The balance of these appointment types has required continual review to ensure the correct demand has been met during the year. All new patients are offered a face-to-face consultation. Initial clinical assessment includes a full clinical and medication history, Aspergillus blood and sputum tests, lung function, radiological imaging, and an assessment of immune status. Baseline quality of life assessments, weight and MRC breathlessness scores are documented. Patients are provided with written information about their disease, the support available and contacts details of the team. When indicated, patients are also seen by a dedicated specialist physiotherapist for chest clearance and breathing control and at patient request, further tailored information such as exercise programmes. We follow a clear diagnostic algorithm to ensure consistent quality of care for all patients.

We have increased the number of face-to-face follow up appointments during the year, prioritising them for those who are unwell, require a change in medication or express a desire to come and see our team. For those seen virtually, our care strategy has not changed. On-going long-term management includes evaluation of symptoms and response to medication, drug side effects, TDM monitoring of drug levels, withdrawing medication when there is no effectiveness as per our agreed clinical pathways, establishing homecare medication delivery direct to the patient every 2 months, liaison with the referring local team and GP to treat co-morbidities and organise necessary tests and delivery of treatment close to home whenever possible. The proportion of investigations performed closer to home has continued to increase, which has often suited patients far better.

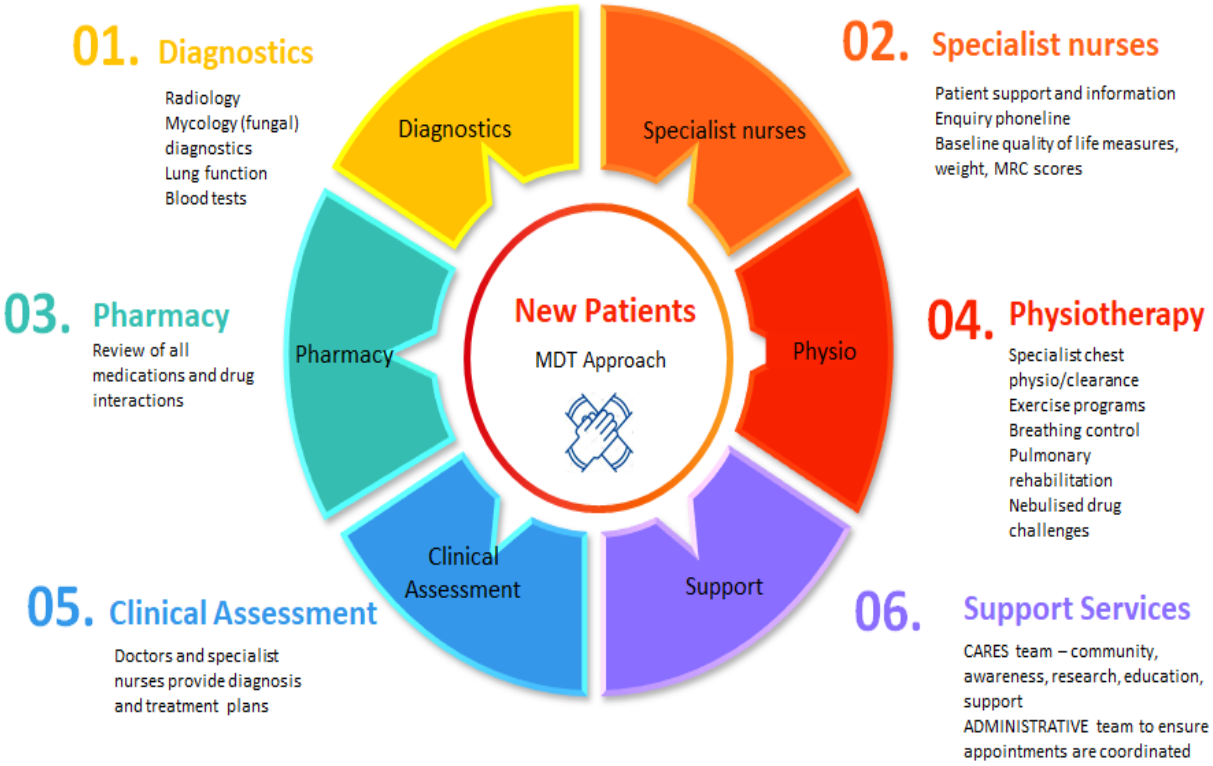
In addition to our out-patient clinics we also deliver short-term inpatient care – this includes evaluation of disease, intravenous therapy, bronchial artery embolisation, surgical resection, training in intravenous line management and delivery of iv antifungals in the community (OPAT). Over the last year we have seen a rise in in-patient activity compared to the all-time low during the onset of the pandemic.

Long-term inpatient supportive or palliative care is beyond the scope of this service. We provide appropriate outpatient information and support regarding symptom palliation/control and end of life care but must maintain close relations with the local parent team to ensure a seamless transfer of care back to the referring hospital when patients no longer benefit from treatment.

It is essential that patient interventions and outcomes are measured continuously, and we undertake a clinically focused programme of audit as agreed with NHS England. This report details the outcomes over the time period 1st April 2021 to 31st March 2022.

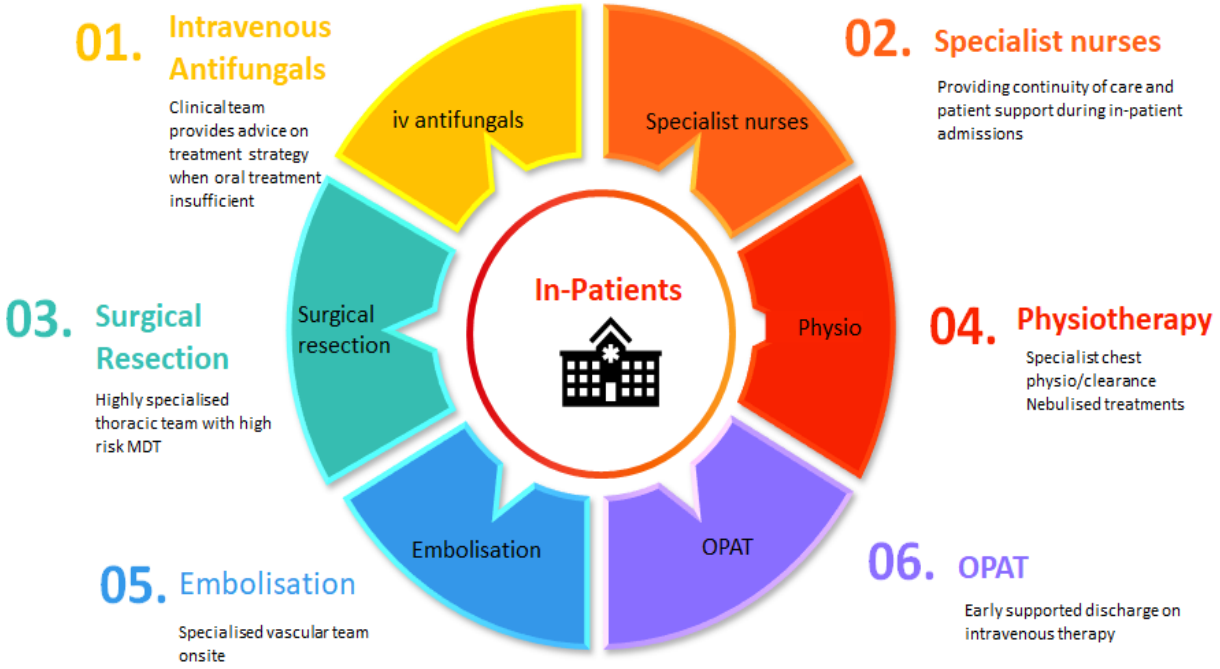
Schematic diagrams of NAC services

NEW PATIENT SERVICES



FOLLOW UP SERVICES

IN-PATIENT SERVICES



2.2 Workforce infrastructure and sustainability

Clinical and administrative personnel
The following clinical and administrative personnel have been vital members of the NAC staffing team during 2021-2022:

Dr Caroline Baxter, Consultant in Respiratory Medicine (3 PAs)
Dr Chris Kosmidis, Consultant in Infectious Diseases (3 PAs)
Dr Gianluca Grana, Consultant in Infectious Diseases (2.5 PAs)
Dr Rohit Bazaz, Consultant in Infectious Diseases (2.5 PAs)
Dr Giorgio Calisti, Consultant in Infectious Diseases (2.5 PAs)
Dr Manuela Barrera, Consultant in Infectious Diseases (2.5 PAs)
Dr Nico Janssen, Consultant in Infectious Diseases (3PAs)
Dr Riina Richardson, Honorary Consultant in Mycology
Mrs Christine Harris, NAC manager (100%)
Mrs Jenny White, Lead Specialist Nurse (60%)
Ms Deborah Kennedy, Specialist Nurse (20%)
Ms Rochelle Baron, Specialist Nurse (20%)
Ms Smitha James, Specialist Nurse (20%)
Ms Niamh Duffy Specialist Nurse (50%)
Ms Lincy Cyriac Specialist Nurse (30%)
Mrs Carol Toner, Band 3 HCA (20%)
Mr Philip Langridge, Senior Specialist Physiotherapist (100%)
Ms Mairead Hughes, Specialist Physiotherapist (50%)
Dr Christopher Eades, Senior Clinical Research Fellow (25%)
Dr Mathilde Chamula, Senior Clinical Fellow (self-funded placement)
Dr George Onwumelu, Clinical Fellow (30%)
Dr Rebecca Thomas, Clinical Fellow (30%)
Dr Guy Mollet, Clinical Fellow (30%)
Dr Katarzyna Pierun, Clinical Fellow (30%)
Dr Laura MacFarlane, Clinical Fellow (30%)
Ms Fiona Lynch, Specialist Senior Pharmacist (40%)
Dr Graham Atherton, Senior Information Technology Architect and Patient engagement (100%)
Mrs Lauren Amphlett, Website design and administrator for patients (100%)
Dr Elizabeth Bradshaw, Medical Writer and Web Manager (100%)
Ms Carmel Marshall, B4 Administration Team Leader (50%)
Ms Soma Pal, B3 Administration and secretarial support (50%)
Vacant Aug 21-Feb 22, B3 Administration and secretarial support (50%)
Vacant Aug 21 to March 22, B2 Administration and secretarial support (50%)
Ms Lucy McLachlan, B2 Administration and secretarial support (50%)

We have had no sustained issues with clinical staff recruitment and have adequate resilience within the team. There has been a higher turn-over of administrative staff including a vacant post.

2.3 Clinical Activity - Referrals, Caseload and In-patient Hospital Activity

The total referrals, patient caseload, in-patient stays and procedures for 2021/2022 are shown below:

Activity Measure	M01	M02	M03	M04	M05	M06	M07	M08	M09	M10	M11	M12	YTD
	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	
Referrals	20	15	17	16	8	16	17	18	21	12	13	11	**184**
New Patients Testing	4	4	9	5	2	5	2	3	3	4	3	5	**49**
Outpatient Follow up attendances	109	110	79	121	86	87	110	91	94	84	71	66	**1108**
Caseload - Band 1	73	73	74	76	79	76	77	73	71	69	66	67	**67**
Caseload - Band 2	275	264	258	255	252	248	249	243	244	240	234	229	**229**
Caseload - Band 3	11	10	10	9	8	8	8	8	8	8	8	8	**8**
Occupied Bed Days	0	0	8	18	4	27	0	20	0	31	9	0	**117**
Inpatient Discharges	0	0	1	2	1	2	0	2	0	1	1	0	**10**
iv Homecare	0	0	0	0	0	0	0	0	0	0	0	8	**8**
Surgical Resection	0	0	0	1	1	1	0	2	0	1	0	0	**6**
Embolisations	0	0	1	1	0	1	0	0	1	0	2	1	**7**
Patient Death	2	7	4	4	1	2	1	5	1	2	8	3	**40**
Discharge from service	13	9	5	8	5	7	3	7	3	7	5	3	**75**

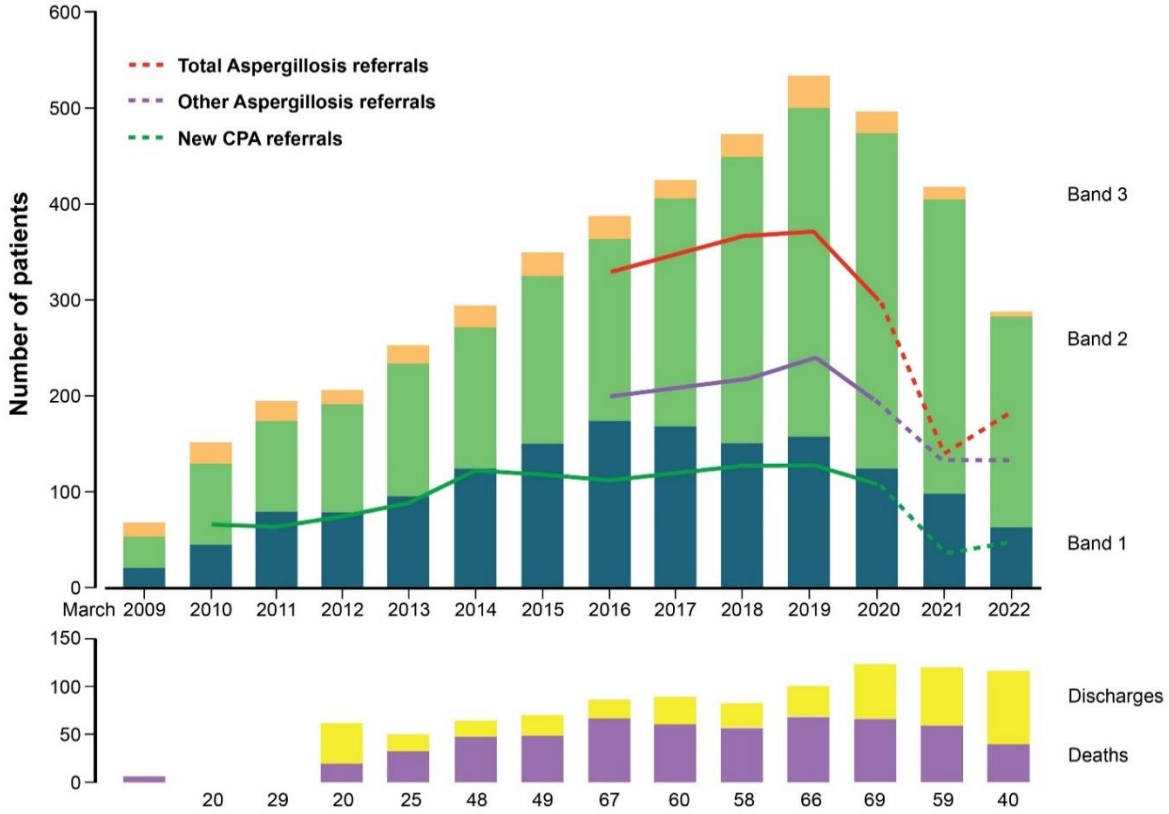
* The NCG funds patients from England and Scotland only
** Appendix 1 shows the clinical definition of case bands

Referrals

There was a total of 184 referrals from England and Scotland during the year 2021 to 2022 that underwent clinic consultation by the service for all forms of Aspergillosis. 49 (27%) of these received a confirmed diagnosis of CPA. There were a further 3 patients from Wales and 1 from Northern Ireland. All new patients are discussed at our weekly MDT to ensure a unified agreed diagnosis and management plan. The proportion of referrals with a diagnosis of CPA remained stable compared to the previous year. In comparison to 2019/2020 the number of new patient referrals has still not recovered to pre-pandemic levels: total referrals 297, new CPA patients 104. This is, in part, due to new ways of assessing referrals due to the pandemic. We have established a National MDT forum in September 2021 which is picking up a significant number of new referrals as seen in the table below (41 patients in 7 months). The National MDT allows physicians from all over the UK to dial into our MDT using MS Teams to share diagnostics and imaging and allow a consensus diagnosis and management plan. In addition to this MDT, we have been providing an increasing volume of written advice and guidance to allow patients to remain closer to home for treatment in the light of the pandemic and travel restrictions. A total of 55 new referrals have been dealt with by providing written advice and guidance. For the year 2022-2023 we will now be reporting the numbers of MDT and written advice and guidance referrals in our monthly NHSE data.

	National MDT	Written Advice Only	Rejected Referrals
Apr 21		8	
May 21		9	
Jun 21		4	
Jul 21		3	1
Aug 21		4	1
Sep 21	4	6	
Oct 21	5	2	
Nov 21	7	11	
Dec 21	4	4	
Jan 22	6	0	
Feb 22	5	1	
Mar 22	10	3	3
TOTAL	41	55	5

NAC Referrals and Caseload 2009 to 2022



Out-patient waiting times

The mean time from referral to clinic consultation was 4.8 weeks (Appendix 2). 1 patient had a long wait (14 weeks) due to personal choice to reschedule appointments. All other patients were seen within 8 weeks of referral. There were 2 transitions from another form of aspergillosis into CPA. 2 patients had delayed registration onto the service due to long diagnostic pathways.

Geographical location

Appendix 2 shows the area of residence from which referrals originated. This data highlights and includes 3 referrals from Wales/1 from Northern Ireland, outside of the commissioned area. Appendix 3 displays maps of the geographical locations (postcode areas) of the new patient referrals and all patients on service. There remains geographical inequity of referrals with a predominance from the North-West of England. We also note the particular lack of referrals from the London area and Southeast. In these areas there are well established fungal respiratory clinics, but care delivered to these patients is not monitored in either patient outcomes or financial implications. In the coming year we will additionally report the postcodes for patients reviewed via National MDT and written advice/guidance.

Patient Caseload

At the end of March 2022, 304 patients from England and Scotland were on service with an additional 11 patients from Wales, 2 from Northern Ireland, 2 from The Isle of Man and 1 from overseas. Patients with CPA are banded according to disease severity, impact on functional ability and presence of antifungal resistance (Appendix 1). During 2021-2022 there has been a fall in patient numbers across all bandings. Band 1 patient numbers fell from 73 to 67 (8%), band 2 fell from 275 to 229 (17%) and band 3 fell from 11 to 8 (27%). This reduction in patient numbers was due to patient deaths and discharges from service, alongside the continued reduction of new patients brought onto the service. There were 40 patient deaths which is a stable proportion compared to previous years: 11% of patient died in 2021-22, 12% in 2020-21 and 13% on 2019-20. There were 75 discharges from service which is slightly higher than the 2 previous years (61 in 202-21, 56 in 2019-2020). The number of patients discharged from service has been increasing due to robust MDT discussions about the need for on-going care of patients stable off therapy as well as a clinical move away from lifelong medication and trials off therapy. Appendix 4 details those discharged from service.

Out-patient follow up appointments have remained proportionately stable to the patient caseload. There were a total of 1108 appointments (1162 in 2020-21 and 1347 in 2019-20), of which 18% were face-to-face, 56% were by telephone consult and 26% were video consult.

	Face-to-face	Telephone	VCR
April 2021	18	59	32
May 2021	19	57	34
June 2021	15	40	24
July 2021	15	68	38
Aug 2021	16	44	26
Sept 2021	14	50	23
Oct 2021	18	63	29
Nov 2021	17	57	17
Dec 2021	12	53	29
Jan 2021	18	49	17
Feb 2021	16	44	11
Mar 2021	18	33	15
Total	196 (17.7%)	617 (55.7%)	295 (26.6%)

In-Patient Hospital Activity

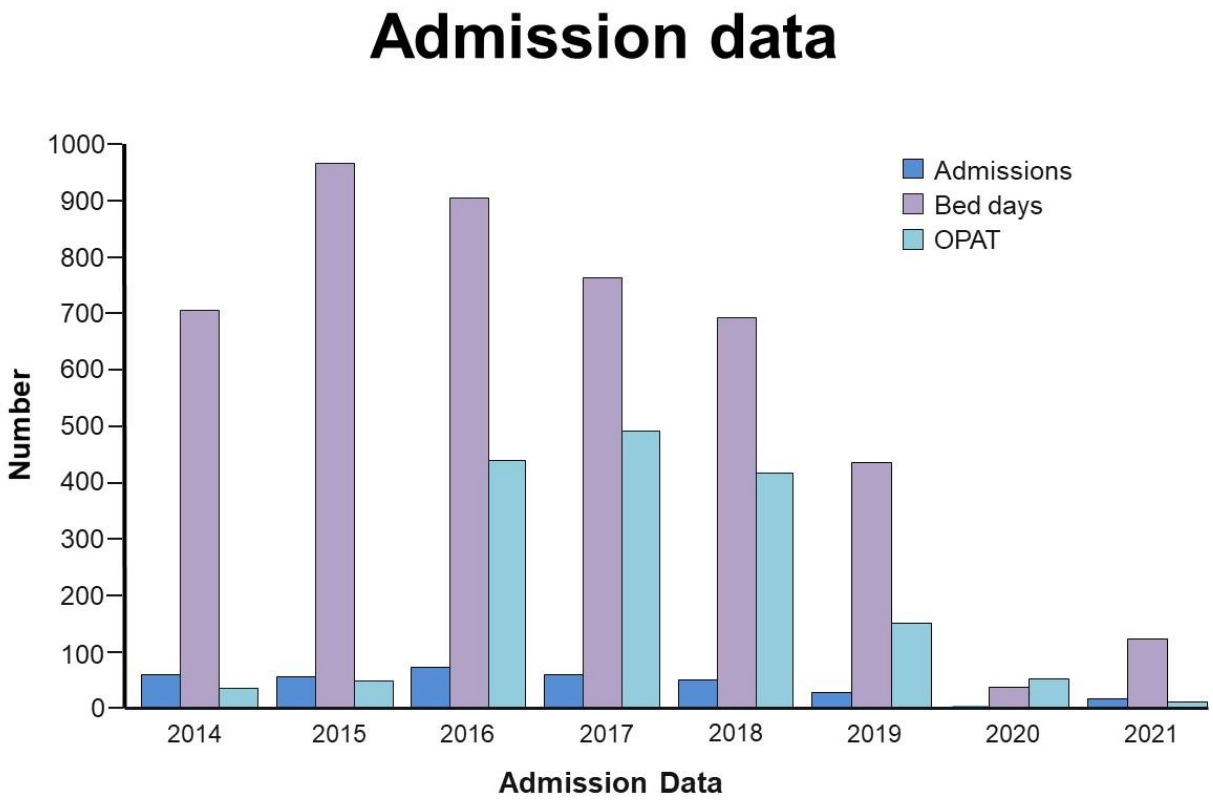
We have seen an increase in in-patient activity this year, more than doubling the number of bed days to 110 compared to 43 last year. This is predominantly secondary to the easing of the Covid-19 pandemic. Despite the impact of the pandemic there has been a continual reduction in hospital admissions and bed days since 2016. Hospital admissions are reducing due to more patients being clinically stable on oral antifungals. The reduced use of iv antifungals has been evident since the introduction of Isavuconazole. In-patient bed days are additionally kept low with the use of the OPAT service and some patients receiving courses of iv antifungals at their local hospital with full monitoring support from our team. Full details of hospital admission data can be found in Appendix 5.

During 2021-22 we have also seen a recovery in our surgical resection rate and embolization rate compared to patent caseload.

	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	2016-17	2017-18	2018-19	2019-20	2020-21	2021-22
Embolisation	16	15	13	9	13	6	20	12	13	6	3	7
Surgical resection	4	3	2	3	4	4	3	6	4	6	1	6

OPAT Activity

The outpatient parenteral antimicrobial therapy (OPAT) team provides intravenous therapy and clinical monitoring for patients deemed suitable to receive their therapy in the community, avoiding a hospital in-patient admission. During the financial year 2021-22 there has been very little OPAT activity with just one patient receiving a course of intravenous micafungin. Our team has also managed to arrange OPAT therapy at distant hospitals for 2 patients. This reduction in OPAT activity mirrors our overall lower use of intravenous antifungals.



2.4 Treatment Outcomes

New referrals

Clinical data for the first year after referral and treatment is presented in Appendix 2. Clinical makers that are monitored include the MRC dyspnoea scale (medical research council), SGRQ (St George's Respiratory Questionnaire), body weight, serum Aspergillus IgG antibody levels and radiological chest imaging.

There were 16 patients who had data pending from 2020-2021. These are presented in Appendix 3 first. 9 patients improved, 4 remained stable and 2 patients died. 1 patient deteriorated and had their antifungal therapy switched.

There were 53 new patients in 2021-2022 (including 3 from Wales and 1 from Northern Ireland). 9 of these patients are pending data to next year to determine clinical outcome.

Of the remaining 44 patients that attended on-going clinic follow up, clinical parameters indicated:

- 21 (48%) showed improvement (4 of whom were able to be discharged)
- 9 (20%) remained stable
- 2 (4.5%) deteriorated despite initial treatment. In response, 1 had antifungal therapy changed successfully and 1 was referred for surgical resection plus change in antifungal while awaiting assessment.
- There were 12 deaths, none of which were directly attributed to CPA

2.5 Antifungal Trial Data

We continue to use n-of-1 trials for voriconazole, posaconazole and isavuconazole Determining a successful outcome of therapy changed in 2020 due to the Covid-19 pandemic. In previous years a successful outcome was determined by demonstrating a 3kg increase in weight or a 12-point improvement in SGRQ after 6 months. Due to the remote nature of many appointments these measures could not be monitored with accuracy. A successful outcome is now determined by demonstrating improvement or stability in radiology and an improvement in Aspergillus antibodies (IgG). We still recognise the importance of measures of quality of life and try to collect this data when possible. Details of antifungal trials and their clinical outcome data this year can be found in Appendix 6. In summary:

- 13 patients completed a 6-month trial of Posaconazole during April 2021-March 2022. 9 of the 13 that completed their trail were deemed successful and continued on posaconazole, 2 patients had to stop medication due to adverse drug reactions and 1 patient died. A further 12 patients have been commenced on Posaconazole but their 6-month outcome review will be due in 2022-23.
- 7 patients completed a 6-month trial of isavuconazole during April 2021-March 2022. 2 of the 7 that completed their trial were deemed successful and continued on isavuconazole, 1 patient failed therapy. 2 patients had to stop medication due to adverse drug reactions and 2 patients died. A further 7 patients have been commenced on posaconazole but their 6-month outcome review will be due in 2022-23.
- 22 patients completed a 6-month trial of voriconazole during April 2021-March 2022. 14 of the 20 that completed their trail were deemed successful and continued on voriconazole, 4 patients had to stop medication due to adverse drug reactions and 4 patients died. A further 3 patients have been commenced on voriconazole but their 6-month outcome review will be due in 2022-23.

Overall success for all antifungal therapy was 60% which is slightly lower than the previous year. This mainly relates to an increase in patients being treated as the pandemic has eased and a larger number of deaths due to co-morbidity. All antifungal

trial outcomes are discussed within our MDT. The outcomes for this year and the previous 2 years are shown in the tables below.

Trials of posaconazole/isavuconazole/voriconazole 2021-2022

Outcomes	Posaconazole		Isavuconazole		Voriconazole	
		%		%		%
Success	9	69	2	29	14	88
Failure	1	8	1	14	0	0
Death/ADR	3	21	4	57	8	12
Total	13		7		22	
Pending	**12**		**7**		**3**	

Trials of posaconazole/isavuconazole/voriconazole 2020-2021

Outcomes	Posaconazole		Isavuconazole		Voriconazole	
		%		%		%
Success	9	64	5	71	7	88
Failure	5	36	2	29	0	0
Death	0		0		1	12
Total	14		7		8	
Pending	**5**		**2**		**6**	

Trials of posaconazole and isavuconazole 2019-2020

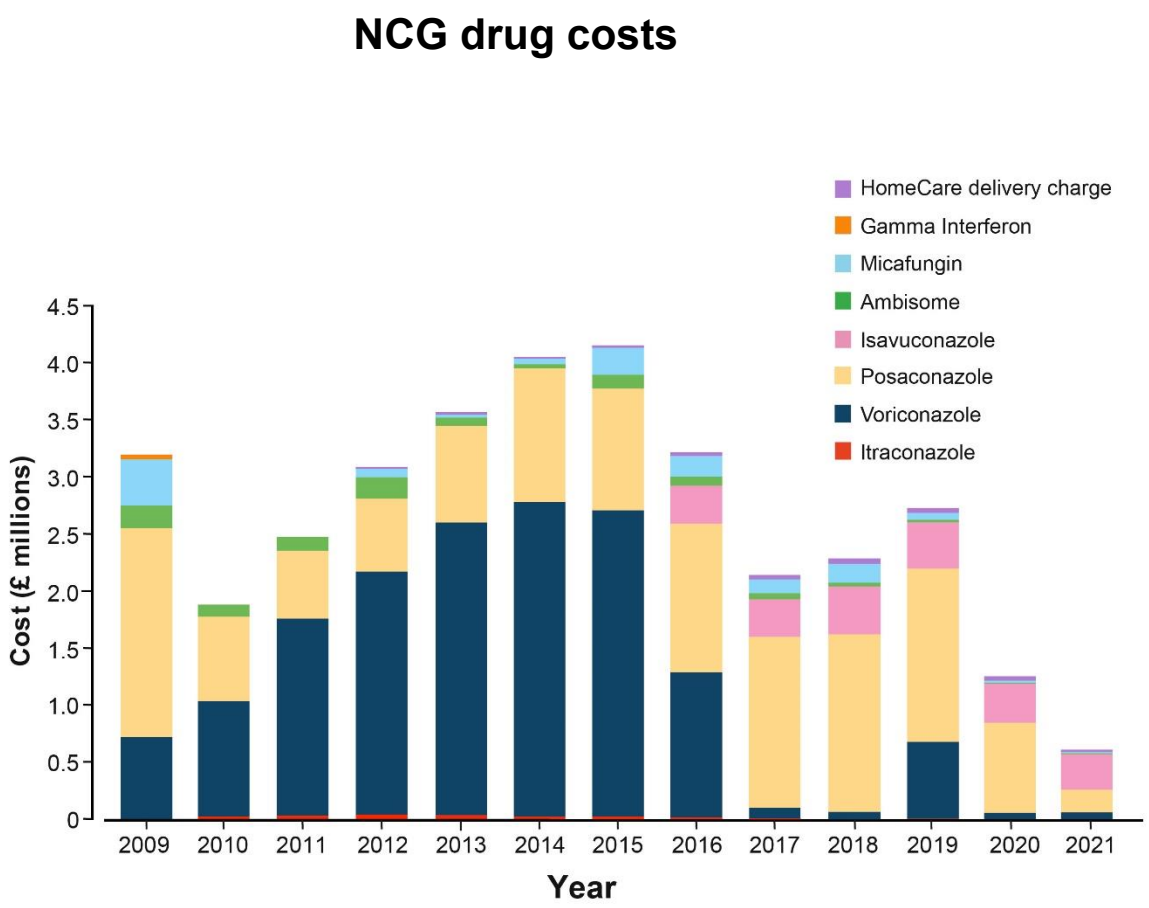
Outcomes	Posaconazole		Isavuconazole	
		%		%
Success	15	48.3	4	33.3
Failure	13	41.9	8	66.7
Death	3	9.9	0	0
Total	31		12	

2.6 Intravenous antifungal therapy

Intravenous antifungal therapy is most often used when azole therapy has failed, resistance has developed or around surgical resection. Appendix 5 demonstrates our iv-antifungal use this year. There were a total of 6 courses of intravenous antifungals given in 2021-2022. There were 4 courses of micafungin, 1 of caspofungin and 1 of AmBisome. Only 1 course was deemed a failure due to adverse effects of renal impairment. The remaining courses were judged successful based on clinical and radiological features.

2.7 Antifungal prescribing and expenditure

Antifungal expenditure has fallen significantly due to Posaconazole coming off patent and generic brands becoming more widely available over the last year. This is similar to 2017 when voriconazole came off patent. Isavuconazole costs have remained stable since the introduction into our commissioning pathway in 2016. As can be seen in our drug trial data prescribing rates are stable for our patient caseload.



3. Specialist Nurse Service

The NAC has a team of highly specialised and dedicated nurses. The service currently has 6 specialist nurses who provide a wide range of clinical and patient support services. During the last year the service has continued to:

- Independently review patients in outpatient clinics via telephone, video and face-to-face appointments.
- Answer patient enquiries and provide support via a patient phone line available 5 days a week.
- Provide high quality care to patients attending clinics and for those admitted to hospital.
- Provide remote antifungal therapeutic drug monitoring through reviewing results daily, adjusting patient doses and communicating these changes to the patient, GP and homecare delivery service.
- Deliver a paid postal service to provide remote blood and sputum testing.
- Senior nurses continue to independently prescribe treatment.
- Senior nurse completed clinical examinations course.
- Developed real time feedback from patients for the nursing team. This led on to the CARES team expanding the opportunity for the whole NAC team to receive this feedback from patients.
- We were recognised for our ongoing hard work during the COVID-19 Pandemic during a Specialist Nurse presentation day.

The NAC nursing service challenges in 2021-2022:

- Complex clinical presentations and outpatient consultations due to patients not seeking alternative healthcare resources
- Supporting patients with their difficulties to have their blood sampling taken, due to GP practices high workload and many discontinuing phlebotomy services.
- Senior healthcare support worker left the team, which has increased the workload for the specialist nurses

Developments for the nursing team 2022-2023:

- Continue to audit with a focus on patient safety. We aim to complete an audit reviewing patients on Itraconazole and reviewing if they have had liver function blood tests done locally by the GP.
- Continue to develop the nursing team service to improve engagement and patient safety. We will achieve this by working alongside the CARES team to improve patient engagement. To develop the nursing team- a scheduled advanced communication course is planned.
- Recruit a senior healthcare support worker and develop this role. Vacancy currently advertised and once the role has been recruited into, we will look to develop the role to help co-ordinate clinic and MDTs, alongside clinical work and administrative tasks.

- The nursing team have received very positive feedback from the surveys sent out post clinic consultations and in the annual report - the team will aim to maintain this standard.

4. Physiotherapy Service

The physiotherapy service is delivered by 2 specialist respiratory physiotherapists. They can support patients in many ways, namely

- **Airway clearance**
  - If retained secretions/ productive cough are causing problems, patients are taught a range of techniques that are appropriate to their individual needs.

- **Nebulised drug challenges**
  - If we plan to use nebulised medications with the potential to provoke bronchospasm (e.g., hypertonic saline, inhaled antimicrobials) their first dose is supervised and evaluated with the co-provision of appropriate patient-centred education)

- **Spirometry**
  - Evaluation of chronic lung disease sometimes requires this, and we can quickly perform flow/volume loops to assist decision making in the clinics

- **Breathing pattern dysfunction**
  - Sometimes patients complain of breathlessness that is not in keeping with their radiology/physiological measures and physiotherapists can assess/treat breathing pattern disorders.

- **Breathlessness management**
  - Simple non-pharmacological measures can improve how patients cope with their lung disease. Physiotherapists can deliver/advise on these interventions.

- **Provision of appropriate exercise programmes including referral/ signposting to pulmonary rehabilitation**
  - Often patients who could be referred to pulmonary rehab aren't by their local services. Sometimes an explanation to the patient or the local care providers by our physiotherapists is all it takes to break down barriers to referral to something that is proven to be a successful intervention for COPD and other chronic respiratory conditions)

- **Nebuliser and inhaler technique advice/ education**
  - Physiotherapists have expertise in the use/ care of these devices and can optimise device use to suit the individual patient)

- **Pelvic floor advice**
    - Chronic cough can contribute to stress incontinence, a problem that is underreported. Physiotherapists ask about his and can give appropriate strengthening exercises and prompt/ discuss referral to local specialist wone's health/ pelvic health physiotherapists.

- **Musculoskeletal advice/ signposting to local services**
    - Many aches and pains are underreported. Physiotherapists can quickly give rudimentary helpful advice and advise on escalation as appropriate to local teams.

- **Sputum induction**
    - Sputum analysis is key in the management of Aspergillus-driven disease. Physiotherapists can effectively assist in the procurement of samples.

Referrals to physio can come from the patients themselves, occur *ad hoc* from face-to-face clinic consultations, arise after clinics/ MDT discussion, or from physiotherapist triage of those attending clinics face to face. There is a minimal wait from referral to assessment by phone/video. Should a face-to-face intervention be necessary there is usually capacity for the patient to be seen within 2 weeks.

1st April 2021- 31st March 2022 the physiotherapy service assessed 141 patients (new assessments) of which 36 did not require further physiotherapy follow up.

Education sessions

To follow on from our online interactive patient talks on breathlessness and exercise, Mairead and Phil gave a brief overview of physiotherapy in our service for World Aspergillosis day 1st February 2022. https://www.youtube.com/watch?v=ke82AaWPctc

Mairead also delivered a teaching session on Aspergillosis to the physiotherapy/ occupational therapy department via Microsoft Teams.

We have taken physiotherapy students for parts of their placement to help consolidate their respiratory skills and to promote the work of the National Aspergillosis Centre.

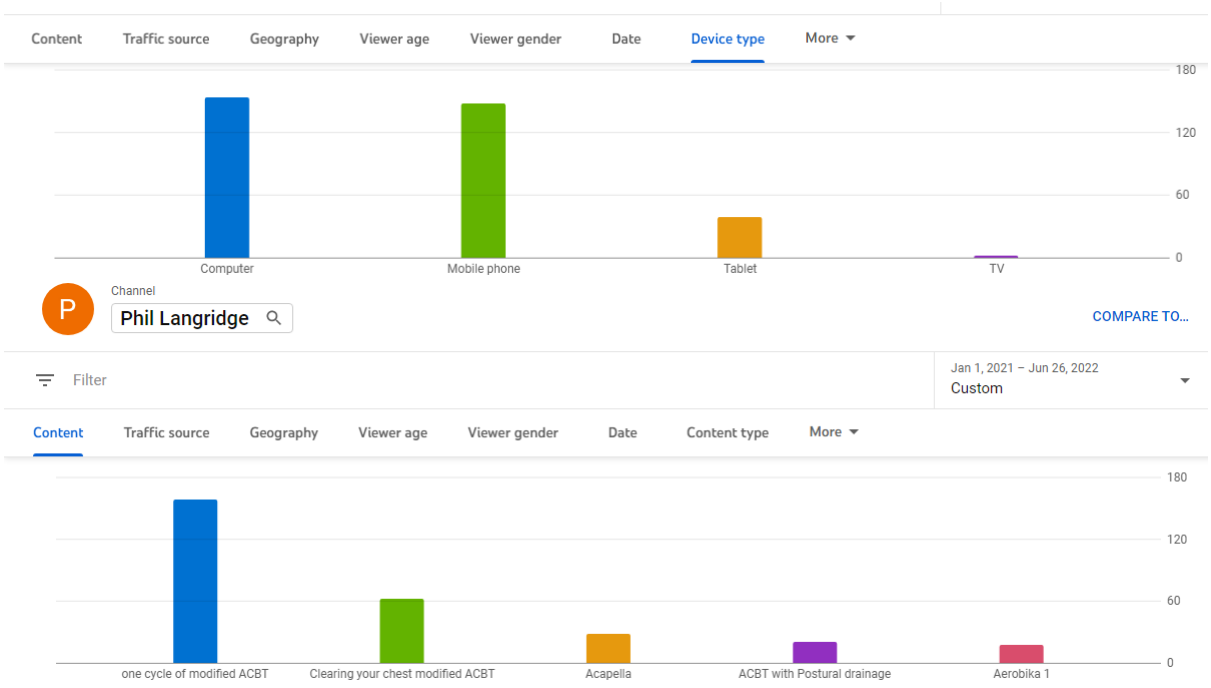
Fundraising

Mairead Hughes ran the Manchester Marathon on 3rd April 2022 in support of the Fungal Infection Trust (FIT). The Fungal Infection trust supports the National Aspergillosis Centre in many ways – not least providing support so that we can run our patient support websites. As it turned out Mairead's support was also called into action as 21 miles into her run she stopped to give medical assistance to a fellow runner. She raised £1,605 – an amazing achievement.

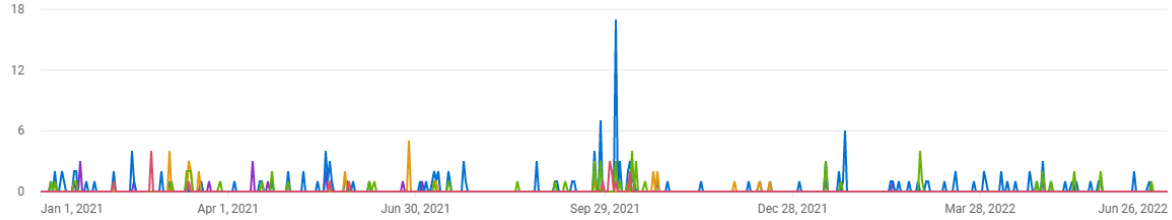
Service development

As for many services, the Covid-19 pandemic has meant 2021-2022 has been a challenging time for the physiotherapy service. We have gone from not being able to see patients face to face at all, to patients requiring a negative Covid PCR test within 72 hours of the planned physio face to face appointment and isolation in the interim, to a negative lateral flow test same day of physiotherapy appointment to no Covid testing requirement (at present).

Our models of working include the capacity for telephone and video appointments. We have welcomed the increasing opportunities to see patients face-to-face in our clinics. Our exclusive range of video resources have been used successfully to support our patients. These videos augment physiotherapy consultations, and the links are only shared with patients who have been in contact with Mairead or Phil. The analytics are as follows:



Content	Views	Average view duration	Average percentage viewed
one cycle of modified ACBT	158 46.5%	2:59	53.1%
Clearing your chest modified ACBT	62 18.2%	7:14	55.4%
Acapella	28 8.2%	4:01	43.4%
ACBT with Postural drainage	20 5.9%	1:18	28.2%
Aerobika 1	17 5.0%	2:46	48.6%
Flutter Shaker PariOPEP	9 2.7%	4:13	67.0%



We have also updated our patient leaflets to include QR codes to further enhance accessibility to our supporting resources.

The challenges ahead

The team remain committed to providing the highest quality and timely physiotherapeutic interventions for our patients. This will involve continued responsiveness to changing infection prevention policies and procedures alongside changing clinical space availability during hospital service restoration.

With the majority of our patients being assessed remotely in the clinics, timely access to the right physiotherapy support is a challenge for many of our patients. Building up our physiotherapy network of contacts, especially over the last few years, has meant that we have been able to accelerate patient access to local respiratory physiotherapy services. Previously when the patients all came face to face there was equity of physiotherapy service provision: a significant challenge now is ensuring that those who don't physically come to our centre still receive top quality physiotherapy input. Key to this is regular training of our clinic doctors to help them understand the physiotherapy "offer", as well as regularly interacting with the patient support groups/ website. For those patients who are unable to access digital resources/content, we support them with written information and telephone assessment. Should the patient and physiotherapist feel that this is inadequate, and the patient can't come to Wythenshawe to see us, we pursue all appropriate local solutions e.g., liaise with community physiotherapy teams etc. to ensure patients get the physiotherapy help they should have. This can require a significant amount of time and creative thinking.

We are in continuing discussions with the directorate about increasing our available clinical space so we can enhance our physiotherapy offer. The implementation of a new electronic patient record/ appointment system within the organisation will provide new opportunities to explore our activity and connect with patients in new ways. We will seek to make the most of these opportunities to continue to provide the best possible care for our patients.

5. Mycology Reference Centre Manchester

Background to the Mycology Reference Centre

The Mycology Reference Centre Manchester (MRCM), the only NHS Mycology Reference Centre, offers a wide range of highly specialised mycological diagnostic services, supporting hospitals and patients throughout the UK. The MRCM operates closely with the National Aspergillosis Centre to meet the evolving needs of the service and to improve fungal diagnostics in the changing environment. The MRCM is a well-established and independent UKAS ISO 15189 accredited service, providing integrated conventional and molecular diagnostic testing. Together with UKHSA Mycology Reference Laboratory, it contributes to the national surveillance of antimicrobial resistance (ESPAUR report). In addition, it holds a considerable research and development portfolio. The MRCM, in partnership with the National Aspergillosis Centre, is the first European Confederation of Medical Mycology (ECMM) Centre of Excellence at Diamond level for the diagnosis and treatment of fungal infections. This was successfully renewed for another four years in January 2021. The vision, scope and research activities can be viewed on the Centre's website: www.mrcm.org.uk

MRCM MISSION

- to be a leading provider of evidence-based mycology reference services embracing all aspects of medical and public health mycology
- to be an externally assessed service that is accredited as safe and of highest quality, delivered by trained, motivated and competent staff
- to provide world renowned training and education of medical and public health mycology
- to contribute to improved health outcomes through teaching, research, and innovation, and continue to be recognised as a Centre of Excellence for the diagnosis and treatment of fungal infections

NHS Manchester University NHS Foundation Trust
UKAS Lab No. 10196
Mycology Reference Centre Manchester
A leading international centre for mycological diagnostics, research and training

Role and Functions

The key aims and objectives of the MRCM are to provide and maintain:

- An exemplary reference mycology service for the National Aspergillosis Centre (NAC), clinics and hospitals in the UK and beyond
- International, national, and local leadership in medical mycology diagnostic services, and training
- A service, which is comprehensive, interpretative, accredited, and appropriate to user needs
- Education and training for all staff, including participation on national and international courses, that is appropriate and relevant to the departmental goals
- A safe, appropriate, and comfortable working environment which is inspirational and motivating that empowers a team environment
- To maintain UKAS ISO 15189 accreditation
- Maintain a research programme in house at the MRCM in collaboration with the NAC and support others undertaking mycology research within the Manchester Fungal Infection Network, within industry, and playing an integral part in clinical trials
- An excellent and close working relationship with the Infectious Diseases Department and the NAC. Good working relationships within microbiology, pathology and with other departments within the Trust, and colleagues in other hospitals and Universities.

Service Strategy

- The MRCM has expanded appropriately to meet the requirements of the National Aspergillosis Centre, with an emphasis on antifungal susceptibility testing and a range of molecular tools. Growth of the MRCM has provided much needed support for NHS research, including clinical trials of new antifungal agents (four during the time span of this report).
- A major innovation has been the establishment of the Mould Surveillance Service: mouldy houses, hospital environments and workplaces. This service has been particularly busy this last year.

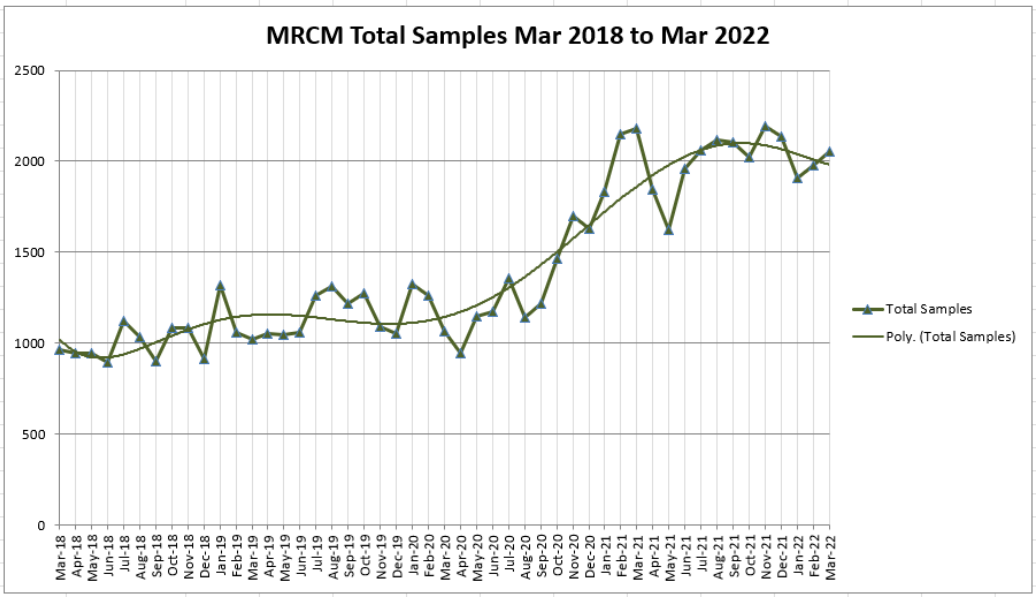
Training, Research and Development

- Provision of clinical mycological training to medical and clinical scientist trainees.
- Contribution to external courses (Institute Pasteur, ESCMID, University of Manchester, University of Leeds, University of Dublin)
- Provision of undergraduate and post-graduate research training and supervision in many areas of medical mycology: BSc research projects, Masters projects, MD and PhD programmes
- Supporting clinical trials and Infectious Diseases research and development projects
- Continued development, evaluation, and validation of new and existing diagnostic tests

Key Achievements – Summary

The MRCM, in its current form, has completed its 13th year of operations. There have been numerous developments, initiatives, and continued growth in its portfolio of tests and activities.

MRCM has had a difficult yet successful year. MRCM total activity for 2021/22 was approximately 24,000 specimens per annum – an increase of more than 33% compared with 2020/21. Over the last four years, our activity has increased by 95%, and our staffing by 46%.



Despite struggling with staffing pressures and increased activity, we have had many significant achievements:

- Successful third UKAS surveillance visit in December 2021. Seven findings were raised, confirmation of clearance of findings expected in summer 2022.
- Successful staff recruitment – two Band 5 Mycology Technologists and two Band 2 Medical Laboratory Assistants.
- Successful re-banding of clerical team member
- Staff excellence awards given.
- Publications: >25 in 2021/2022, in collaboration with national and international partners, plus co-authors of global guidelines and clinical tools:
    - Systemic fungal infections (Medicine, 2021)
    - Aspergillus in indoor environments (Encyclopaedia of Fungi, 2021)
    - An overview of using fungal DNA for the diagnosis of invasive mycoses (Expert review of Molecular Diagnostics, 2022)
    - Global guideline for the diagnosis and management of rare yeast infections: an initiative of the ECMM in cooperation with ISHAM and ASM (Lancet Infectious Diseases, 2021)
- Successful MALDI-ToF business case and capital bid for new thermal cyclers
- Expansion of pan-fungal PCR of blood and tissue specimens nationwide

- Successful funding for staff further education including:
  - BTEC Level 4 Diploma in Healthcare Science Apprenticeship
  - BA(HONS) Business Management Professional in Health and Social Care
  - Upskilling funding from Health Education England – two grants awarded for top-up modules and IBMS registration portfolios.

Representation on National and International Committees:

- EUCAST Antifungal Susceptibility Testing Committee as a Collaborating Laboratory. Dr Caroline Moore (CBM) is the UK representative for the European Committee on Antibiotic Susceptibility Testing (EUCAST) Subcommittee on Antifungal Susceptibility Testing
- Dr Riina Richardson (RR) is the Chair of the UK Standards for Microbiology Investigations (UK SMI) Bacteriology Working Group and a member of the Steering Committee
- Joint contribution with UKHSA Mycology Reference Laboratory to the English surveillance programme for antimicrobial utilisation and resistance (ESPAUR)
- Testing laboratory for UK NEQAS for Microbiology – Mycology identification and susceptibility schemes
- Test centre for all Fungal PCR Initiative (FPCRI) schemes – fungal PCR for Aspergillus, Candida, Pneumocystis, Mucorales and tissue. RR is the lead for the Pneumocystis Working Group.
- RR is the UK representative for the European Confederation of Medical Mycology (ECMM) Excellence Centre Assessment Committee setting the standards and accrediting centres for the diagnostics and management of mycoses globally.
- Prof Malcolm Richardson (MDR) is a co-author of Global guidelines for the diagnosis and management of mucormycosis and rare moulds. Lancet Infectious Diseases, 2019 & 2021.
- RR is the Mycologist on the British Association for Sexual Health and HIV (BASHH) UK National Guideline on the Management of Vulvovaginal Candidiasis working group.
- RR is actively involved with the European Society of Clinical Microbiology and Infectious Diseases (ESCMID) working groups and have been invited to contribute to the development of European guidelines on fungal infections (Candidaemia guideline, Rare yeasts guideline).
- RR was elected onto the ESCMID Education subcommittee in 2022.
- RR is on the British Society for Antimicrobial Chemotherapy Grants committee
- CBM is Honorary Treasurer of the British Society for Medical Mycology

Research and Test Evaluation Activities:

Consolidation of test portfolio offered for the benefit of CPA patients:

- Ongoing experience regarding sensitivity testing on *Aspergillus* isolates to include terbinafine, micafungin, isavuconazole, and investigational compounds, for example, ibrexafungerp.
- Real-time PCR for Aspergillus in respiratory secretions and blood

- Molecular identification of fungi, including unusual *Aspergillus* species. This is a nationwide service
- Monitoring of NAC/CPA patients houses, workplaces for *Aspergillus*
- Provision of mycology services to national and international pharmaceutical companies who are developing new antifungal drugs.

Publishing Activities:

- Reporting MRCM audit data on resistance and novel antifungal susceptibilities
- Participation to international audits on CAPA and candidaemia.
- Contributions to national and international guidelines
- Contributions to National Aspergillosis Centre and the Manchester Fungal Infection Group publication output
- Numerous clinical and laboratory audits presented at national and international meetings and written up as publications:
    - Aspergillosis in VAP patients (published)
    - Overview of using fungal DNA for the diagnosis of invasive mycoses (published)
    - Prognostic impact of bronchoalveolar lavage galactomannan and *Aspergillus* culture results on survival in COVID-19 ICU patients: a post-hoc analysis from the European Confederation of Medical Mycology (ECMM) COVID-19-associated pulmonary aspergillosis (CAPA) study (published)
    - Risk factors for intra-abdominal candidiasis in intensive care units: results from EUCANDICU study (published)
    - Incidence of candidaemia in prolonged veno-venous extracorporeal membrane oxygenation (published)
    - Risk factors and outcome of pulmonary aspergillosis in critically ill coronavirus disease 2019 patients – a multinational observational study by the European Confederation of Medical Mycology (published)
    - Impact of airway *Exophiala* spp. on children with cystic fibrosis (published)
    - Meteorological factors influence the presence of fungi in the air: a 14-month surveillance study at an adult cystic fibrosis centre (published)
    - Clinical outcomes in 10-year follow-up of *Aspergillus* disease phenotypes in adult cystic fibrosis patients (submitted for publication)

Laboratory and Staff Objectives

Objective	Achieved by	How will we know we have succeeded?	How will this be monitored?	Comments
To continue to support our staff and their wellbeing to ensure their resilience during the ongoing Covid-19 pandemic and beyond	• Weekly huddles to discuss issues and to provide reassurance • A 'catch-up' meeting six months after appraisals • Reminding staff that senior staff have a 'door always open' policy	• Staff retention • Improvement in appraisal review wheel scores	• Staff appraisals	
To implement a robust training plan to ensure all staff are trained across tests we offer.	• Senior staff meeting to discuss training needs. Devise a training rota and schedule in dates to commence training of staff.	• Staff competent in a range of tests • Granting annual leave becomes easier	• Using the competency tracker	• Flexible career progression to recruit and support those from academia and industry with specific mycology skills beneficial for the service
To expand our testing portfolio keeping pace with new technological and treatment developments	• New tests and technologies discussed at Senior staff meetings	• New tests and technologies available at MRCM	• Senior staff meetings	• Implementation of MALDI-ToF for fungal identification • Replacement of automated DNA extraction platform
To continue to support staff with further education, including IBMS and other professional body registration portfolios	• Continue to attend DLM Competency and Training Group Meetings to discover new opportunities • Continue to offer access to virtual conferences and courses	• Staff in the department become IBMS registered • Staff have a variety of reflective statements in CPD portfolio	• This will be monitored in the laboratory's quarterly quality reports.	• Supporting staff with further education continues to develop the laboratory's portfolio and knowledge which allows us to provide the best possible care to our patients. Additionally, career progression boosts morale and staff retention.
To review our test portfolio and to consolidate centralised mycology diagnostics in line with MFT Infection Strategy	• Continue to contribute to the infection strategy development and implementation	• All MFT patients have access to timely high standard fungal diagnostics and advice	• Quarterly reports	• This includes provision of tests as per NICE COVID co-infection guideline for all MFT patients
To formalise the back up for clinical advice	• Recruiting and training ID consultants on the on-call rota	• Training done and rota in place	• Monitoring of rotas	• The merger of ID services and on-call rotas will lead to less consistent mycology expertise amongst those on call.

Quality and IT Objectives

Objective	Achieved by:	How will we know we have succeeded?	How will this be monitored?	Comments
To encourage staff to take an active role within the QMS system, to allow us to catch up with QMS documentation and audit schedules and maintain our UKAS ISO 15189 accreditation.	• Implementing twice monthly quality huddles. • To provide training on how to undertake quality tasks, including documentation review and completing, addressing, and closing non-conformances.	• Documentation review percentage is ≤10% • Non-conformances are addressed and closed within the timeframe documented in MRCM-QU7	• This will be monitored in the laboratory's quarterly quality reports and on the QMS Recovery Plan, 'LIVE' document	
To improve within laboratory TAT for Superficial Mycology Specimens.	• Increase number of staff competent in reading and reporting superficial mycology specimens. This will be done by providing more training. • Update the current TAT to a more realistic TAT*	• When 90% of our Superficial Mycology specimens are reported within the stated TAT	• This will be continued to be monitored in the quarterly quality reports • Update to be given at Quality meetings and Senior meetings.	*Currently our TAT for culture is 1-3 weeks. This is unachievable as culture incubation time is 3 weeks, as per SMI guidelines. Increasing TAT to 4-5 weeks allows time for identification, especially if the fungus requires molecular sequencing
To improve the total (patient to patient) TAT for all MRCM tests within MFT	• Streamlining specimen transportation • Beaker/HIVE	• Audits	• Audits	This has to be improved. Currently significant delays between MFT sites.
To continue to engage with the HIVE EPR programme, to implement the Beaker.	• Working with the HIVE analysts in preparation of the go-live date in September 2022.	• Successful implementation of the new system	• This will be monitored by the laboratory's change control process and via Rapid Decision Groups	

Financial Expectations for 2022/2023

- To maintain increased levels of activity and thus secure funding for additional staffing costs, particularly for clinical authorising and advice, and consumable costs:
    - due to increased clinician awareness and rapid TAT, demand for our fungal biomarker service remains high
    - superficial mycology workload increased by over 30% from 2020/21 to 2021/22

- To seek to increase external client income, both clinical and veterinary diagnostics, and environmental services. This is dependent on increased staffing and effective marketing.
- Further external income from providing centralised diagnostic services for clinical trials of new antifungal drugs – Pulmatrix & Pulmocide and other trials to be restarted during 2022/23 following Covid-19 pandemic.

Anticipated cost pressures

- Continued high activity, especially fungal biomarkers service, from MFT and external sources
- Loss of North Manchester General Hospital (NMGH) income after transfer to MFT in September 2022
- Under-recovery of external income whilst P2P block payments are in place (until July 2022), and uncertainty over new financial arrangements of system funding
- Superficial mycology service – negotiations with GP Commissioners (or Integrated Care Boards) re pricing tariff

Deliverables for 2022/2023

Target	Milestones	Timelines	Comments
Implementation of HIVE Beaker LIMS	• Build software • Participate in phase 1 and 2 testing • Staff trained as peer trainers and superusers • Staff end user training	• Software build and testing to be completed July 2022 • Peer trainers and superusers training commencing June 2022 • Staff end user training commencing July 2022	

Implement Q-pulse Enterprise to support UKAS accreditation and harmonisation of QMS processes	• Participate in quality meetings relating to Enterprise • Migration documentation • Migration of asset module • Build of other modules (audit and NC) • Staff training	• Migration of modules June 2022 • Use of system May 2022	• Ideagen to assist with database build
Maintain UKAS ISO 15189 accreditation	• Recovery of QMS – monitored via Recovery Plan • Preparation for full UKAS ISO 15189 inspection	• Ongoing	• UKAS inspection expected December 2022
Introduction of new EUCAST breakpoints for yeast and mould	• Analysis of impact • IT requirements • Staff training • User education	• Prior to September 2022	• In advance of Beaker • Change control/memos needed
Introduction of new fungal organism taxonomy names	• Analysis of impact • IT requirements • Staff training • User education	• Prior to September 2022	• In advance of Beaker • Change control/memos needed
Implementation of MALDI-ToF technology for fungal identification	• Installation of equipment • Validation of the test for yeast identification • Validation of the test for mould identification	• Equipment arriving in lab Spring 2022 • Validation Summer 2022	
Replacement of automated DNA extraction platform	• Work with Procurement to identify candidate equipment • Trials with potential equipment • Work with Procurement and Finance to procure chosen equipment • Validation of chosen equipment	• By December 2022	
Introduction of *Aspergillus fumigatus* specific qPCR assay	• Validation of the assay • Begin offering service	• By December 2022	• Dependent on automated DNA extraction platform
Introduction of *Aspergillus* qPCR for blood specimens	• Submit new test application • Validation of the assay • Begin offering service	• Throughout summer 2022 with support from ID Clinical Fellow	• Dependent on automated DNA extraction platform

Work towards introduction of Mucorales PCR	• Evaluation of existing commercial kits • Contribution to FPCRI EQA development	• Ongoing	• MRCM is a FPCRI member laboratory
Disaggregation of North Manchester General Hospital	• Understand any increased activity • Understand the financial implications	• Prior to September 2022	• MRCM already undertakes NMGH sent from Oldham
Audit and manage MRCM test demands	• Review internal guidelines and audit compliance with these • Beaker/HIVE	• Ongoing	
Isavuconazole TDM	• No equipment required, assay to be performed by Biochemistry Dept, Wythenshawe Hospital. • Continue discussions with Biochemistry Department	• Ongoing	• Validation start date dependent on overtime funding availability. • MRCM to start duplicating specimens May 2022

Other Aims for 2022/2023

- We consistently perform well in our current KPIs (biomarker TATs and rejected specimens), so we will look to add to our KPIs to monitor other aspects of our service
- Challenge ourselves further with molecular sequencing of moulds

Staffing, Quality, IT

Staffing

- There is currently a vacant band 6 IT position. It is hoped that this position will be appointed before summer 2022.
- The vacant Quality and Training Coordinator post (band 6) has been converted into a band 7 Quality Manager post (currently undergoing banding); we hope that this position is appointed before the end of 2022.
- Following the retirement of Professor Malcolm Richardson in 2020, reconfiguration of the senior management team is ongoing:
    - Re-banding of Principal Clinical Scientist to Band 8C as deputy Head of Service
    - Re-banding of Senior Clinical Scientist to Band 8A
- Continue to participate in DLM Competency and Training Group meetings to give staff the opportunity to attend courses and be involved in further education.

This will improve staff training and development and boost morale to ensure staff retention.
- Focus on staff wellbeing and continued emotional support for staff.

Quality

- The MRCM expects to retain their UKAS ISO 15189 accredited status following a successful surveillance visit in December 2021, with minimal findings. Clearance of these findings is expected summer 2022.
- There is an active programme of service improvement mediated by audit and the quality team are crucial to ensuring that the service delivered continues to be of the highest quality. Due to the continuation of increased test activity, the QMS performance has slipped for Quarter 1, 2 and 3. A QMS recovery plan has been devised which is expected to be in place for the next 12-18 months. Sticking to this plan is crucial for maintaining our UKAS ISO 15189 accreditation at the next assessment.
- All tests are registered with external quality assurance schemes where applicable and all performance is monitored. There are regular departmental quality meetings.
- There are multidisciplinary and technical/clinical meetings which help to create an informed dedicated team.
- We have structured training programmes and hold IBMS registration training status.
- Development of Enterprise Q-pulse system will allow us to implement new ways of working. New procedures will encourage staff to have an active role within the Quality Management System, including completing non-conformances and reviewing documentation. Training to be given.

Information Technology

- Maintain and update, when necessary, the MRCM website for external users, to continue to provide information of tests and guidelines.
- To continue to promote Mycology and MRCM via MRCM Twitter.
- Provide user education via the MRCM website, MRCM Twitter and the GP newsletter.
- Continue to be involved with the development and implementation of HIVE Beaker LIMS.
- Continue to be involved with the development and implementation of the DLM wide Enterprise Q-pulse.

SWOT Analysis

Strengths:

- Strong scientific and clinical leadership
- Professional expertise, over 100 years of experience in the field of Medical Mycology, and skills mix of all staff
- Close working relationship with the Infectious Diseases service
- Consultant cover for Clinical Lead annual leave organised
- Recognition throughout the UK and Europe, as reflected by UKAS ISO 15189 accreditation and the recent renewal of award as an ECMM Centre of Excellence in Clinical and Laboratory Mycology and Clinical Studies

- New, informative website and marketing platform
- Approaches by UK and US pharma companies to service clinical trials of new antifungals
- UK strategic influence: recognition by various NHS organisations as a centre of expertise as reflected by invitations to join various advisory group and committees
- Relationships with wider public health and academic communities
- Providing link between hospital and community
- Partnership with the component departments of the Division of Laboratory Medicine (MFT)
- High quality accommodation with modern facilities and equipment
- Integral part of the Manchester Fungal Infections Group, University of Manchester, and access to a range of molecular platforms and biological imaging facilities
- Active Research and Innovation programme
- Strong publication activities
- Molecular expertise
- National reputation for the provision of medical mycology training for all levels of non-medical and medical staff
- Networking and communication across the global mycological community
- Molecular epidemiology: capacity and expertise to develop typing systems for *Candida* and *Aspergillus* isolates
- Respected clinical liaison across the UK and globally, as evidenced by invitation to join the ECMM Expert Consultation Service for medical centres around the globe seeking advice when there is no fungal infection consultant available, and to join European-wide audits and clinical trials of new antifungal drugs
- Multiple opportunities for income generation, with support from the DLM teams
- Good engagement with National Aspergillosis Centre Commissioners
- The EUCAST testing laboratory for UK NEQAS for Microbiology Antifungal Susceptibility Scheme
- The MRCM is the UK's EUCAST collaborative laboratory
- Test centre for all Fungal PCR Initiative (FPCRI) schemes – fungal PCR for *Aspergillus, Candida, Pneumocystis,* Mucorales and tissue

Weaknesses

- No full-specification Category Ill containment facility
- Limited resilience in staff numbers, given persistently high activity
- Patchy use of our services locally due to financial drivers blurred by centrally subsidised UKHSA fees. As a result, MFT patients have unequal access to e.g., up to date high quality molecular testing including screening for resistance mutations.

Opportunities

- Expansion of the National Aspergillosis Centre: new specification and increased capacity being discussed with NHS England specialist commissioned services team. This will translate into increased funding for MRCM to support additional staff and increase in activity
- To become an integral part of the MFT Infection Strategy

- Development of a near patient (point of care) portfolio with the commercial development and introduction of lateral flow devices for fungal antigens and antibodies
- Expansion of molecular services
- Marketing of services to a broader client base
- Evaluation of new molecular platforms
- Expansion of training programmes for UK and oversees trainees
- HIVE electronic patient record system and Beaker LIMS for clearer and faster reporting as well as audit and demand management

Threats

- Retraction of laboratory space by University of Manchester
- Maintaining a high quality fully established consultant workforce
- Retaining highly dedicated staff with clear career progression

Future Plans and Timelines

Key Target	Comments
Introduction of new assays including: • *Aspergillus* IgG/IgM LFD • *Aspergillus* galactomannan LFA as POC test • Introduction of *Aspergillus* PCR on blood specimens • Mucorales PCR • Re-introduction of Pneumocystis PCR on saliva and respiratory specimens • PCP resistance testing	• This is a long-term plan over the next five years. • Whilst partial validation has been performed for some of these assays (through university projects), it is unlikely that an extension to scope will be ready for 2022 UKAS inspection. New test applications will be submitted.
Improve user communication and education to ensure we are meeting demand and providing a quality service	• Continue to engage with users via user surveys. • Be involved in hospital and GP newsletters
Keeping up to date with new technologies and tests to ensure we are at the forefront of Mycology	• This is a long-term plan. Implementation of new tests and technologies will be rolling departmental goal. This will be achieved by encouraging staff to attend conferences, courses and reading new literature.
Continue to consolidate working processes and streamline mycology testing across MFT	• Analyses of TAT and workflow, resolving any barriers found
Improve access to and use of fungal diagnostic tests to support reduction of unnecessary empiric use of antifungals	• Continue to engage with users via user surveys.
Retention of experienced and dedicated staff	• This is a rolling departmental goal. MRCM have 21 members of staff with over 100 combined years of

	experience. It is crucial for our department, patient care and the world of mycology that we retain staff. This is achieved by boosting morale, providing training and further education, and creating a friendly and caring environment for staff to work in.
To continue to market the test scope we ffer	• This is achieved by communications to external establishments via the MRCM twitter, MRCM website and the hospital and GP newsletters. Additionally, staff attending conferences and courses will be able to promote our services.

Summary

Over the last four years, our activity has increased by 95%, and our staffing by 46%. We continue to grow and innovate, embracing further opportunities to develop and expand our unique service: increasing staffing to sustain growth, and investment in state-of-the-art IT solutions and technologies. Realising these opportunities will be the focus of our strategic plan; this aligns with DLM, and ultimately, MFT vision.

Successful implementation of our strategic plan will drive us towards our vision, and ultimately improve patient care.

6. Mortality Report

Morbidity and mortality meetings have continued monthly over the last year. The aim is to discuss the care that the NAC team have provided to all CPA patients who have died while under our active care. The cause of death is not always available due to the difficulty in obtaining death certificate information. All consultants and fellows present cases in monthly rotation. A mortality review proforma is completed for every patient discussed; the proforma includes review of the following points:

1. Problems in establishing diagnosis/ performing appropriate diagnostic tests
2. Problems in clinical monitoring (including failure to plan, to undertake, or to recognise and respond to changes)
3. Problems in administered CPA treatment (appropriate/timely/safe use of antifungals)
4. Problems not fitting the categories above

For the period April 2021 to March 2022, 35 of 40 patient that died have been discussed by year-end. The key issues identified, and lessons learnt are presented below:

1. The diagnosis of CPA was revisited in a patient who was prescribed antifungals and developed side effects. It was felt at the mortality meeting the diagnosis could not be confirmed radiologically and therefore the patient was exposed to toxicity unnecessarily. It was agreed that this would be unlikely to happen now as we discuss every new CPA diagnosis at MDT.

2. A CPA patient was started on IV micafungin in another trust; however, no documentation was present in our medical records. It was thought likely to have come from NAC as there was evidence of azole resistant aspergillus at the Mycology Reference Centre. It was agreed that documentation of external advice was inadequate in this case. We now document external advice via a communication form on EPR so this is less likely to happen.
3. A CPA patient was started on voriconazole and the blood levels where subtherapeutic on two occasions. On both occasions there was a delay in acting on the result (11 days and 37 days respectively). It was agreed no harm resulted as the patient's CPA was controlled. Our new electronic patient record HIVE will prevent this.

7. Statutory reports

7.1 MRSA

No cases of MRSA were reported.

7.2 *C. difficile* and CPE infections

No cases of *C. difficile* infection were reported.
No CPE (carbapenamase producer) cases were reported

7.3 Serious Untoward Incidents (SUIs)

No SUI's were reported.

7.4 Complaints

There were no informal or formal complaints in the Year 2021-2022

7.5 Hospital Incident Reporting System (HIRS) alerts

	SUI	HIRS	Complaints
2013-14	1	0	3
2014-15	0	0	1
2015-16	0	1	0
2016-17	0	0	1
2017-18	0	3	0
2018-19	0	1	0
2019-20	0	2	0
2020-21	0	1	1
2021-22	0	0	0

8. Audit and Quality Improvement Report

The NAC has a strong programme of audit and quality improvement that runs continuously throughout the year. Our clinical fellows are actively engaged in this programme allowing opportunities for publications and conference poster presentations. Audits are presented at departmental teaching seminars.

Ongoing audits:

1. Retrospective assessment of itraconazole treatment in Aspergillus bronchitis

This audit is examining the rate of exacerbations before and after itraconazole treatment, as well as the degree of toxicity to itraconazole leading to discontinuation, in patients diagnosed with Aspergillus bronchitis. Data collection has finished and is being analysed.

2. Risk factors for CPA development following TB treatment

In collaboration with PHE Northwest, we will determine the cumulative incidence and the risk factors for developing CPA, in patients who complete TB treatment in the Greater Manchester area. This work will lead to earlier diagnosis of CPA following TB treatment. This work is at the stage of data collection.

3. Risk factors for CPA development following lung cancer treatment

In collaboration with the Christie and cardiothoracic surgeons at MFT, we are determining the cumulative incidence and risk factors for CPA development following treatment for lung cancer. This work will raise awareness for CPA as a complication of lung cancer. This work is at the stage of data analysis.

4. Audit of voriconazole level monitoring.

We are collecting data on the proportion of patients who had sub- or supratherapeutic levels of voriconazole. As there is a practice to start with lower than standard doses of antifungals in order to avoid toxicity, we aim to check whether this practice results in subtherapeutic levels. This work is at the stage of data analysis.

9. Research and Publications

During 2021-2022, there were 14 peer-reviewed journal articles published by our staff, which are listed in Appendix 7. This was lower than our historical average, largely due to the effects of the COVID-19 pandemic, which created exceptional time pressures on our clinical and laboratory staff. However, we have several existing clinical trials that will soon resume recruiting participants and we recently won a NIHR grant to conduct a randomised controlled trial into immunotherapy for CPA (see below).
We have continued to be active in disseminating our clinical cases, audits and research findings at field-specific conferences. As page fees with journals continue to

rise, this is becoming an increasingly attractive option for sharing our expertise with colleagues around the world.

IFNγ

A weakened immune system is one of the underlying risk factors for developing *Aspergillus* infections. For several years we have been investigating whether CPA patients could benefit from being treated with interferon gamma (IFNγ), an immune-stimulating drug already available through the NHS for other conditions.

This year we published a paper in Journal of Infectious Diseases (Colombo *et al*, 2022) that found deficiencies in the immune responses of CPA patients, which were associated with a lower chance of survival. Blood samples from 133 patients showed a weakened immune response against beta-glucan (fungal cell wall), lipopolysaccharide (bacterial cell wall), zymosan (yeast cell wall) and two human immune signalling molecules (IL-12, IL-18). Crucially, patients who produced the least IFNγ were less likely to survive.

We previously published a preliminary study that reviewed the charts of 20 patients who had been prescribed IFNγ as salvage therapy after antifungal treatment failed, which suggested it could reduce the frequency of exacerbations and hospital stays. This year, Dr Chris Kosmidis won a grant application from National Institute for Health and Care Research (NIHR) to scale this work up as a randomised controlled trial. This is a crucial stepping stone towards incorporating this therapy into CPA care.

This cutting-edge work would not be possible without the critical mass of expertise and large patient group at NAC. We benefit greatly from working with the immunology department at MFT and recently invited Dr Tomaz Garcez from their team to give a lunchtime training session to update our staff about when and how to refer NAC patients to the immunology service.

Indoor exposure to moulds

Minimising exposure to mould and spores is one of the most popular questions discussed in our patient support groups, but unfortunately there is a huge amount of online misinformation and low-quality scientific papers on this topic.

Spores are a well-known asthma trigger but very little is known about how exposure affects patents with COPD and/or CPA. A questionnaire-based study found that patients were more likely to have frequent hospital appointments or antibiotic treatment if they had certain exposure risks, such as allowing guests to keep their shoes on while visiting (Kosmidis *et al*, 2021).

The Mycology Reference Centre Manchester (MRCM) offers an environmental survey that estimates the severity of mould hazards within buildings, by measuring the quantity of spores and identifying the fungal species present. They recently published the results of sampling air from the Manchester Adult Cystic Fibrosis Centre (MACFC) over the course of 14 months. *Aspergillus* spores were more abundant during summer and in bedrooms that had an openable window (van Rhijn *et al*, 2021).

Other

- NAC uses patient-reported outcome measures (PROMs) such as the St George's Respiratory Questionnaire (SGRQ) to help guide patient treatment. We found that deteriorating SRGQ scores were associated with relapse of CPA after antifungal therapy is stopped (Bongomin & Otu, 2021)

- We contributed to a large ECMM study of COVID patients who subsequently developed invasive aspergillosis. Risk factors included older age, more invasive ventilation and treatment with tocilizumab (Prattes *et al*, 2021).
- A joint project between MRCM and MFIG staff looked at the genomes of several strains of *Penicillium* mould isolated from patients attending NAC. They carried a new version of the CYP51A gene that made them resistant to azole antifungals (Van Rhijn *et al*, 2021).
- Another MRCM/MFIG project found that the strength of immune response mounted by the lungs varied depending on the amount of protein-degrading enzymes secreted by different strains of *Aspergillus* during germination (Rowley *et al*, 2021).
- MRCM staff noticed that the *Aspergillus* PCR kit we currently use can give a positive result in the presence of other species of mould (e.g. *Penicillium*). This would not affect the care of our CPA patients because of how we combine this with other tests but is important for clinicians to be aware of in other settings. These results were presented as a conference poster at the Advances Against Aspergillosis & Mucormycosis.
- We also contributed to a review by the Fungal PCR Initiative describing the diagnosis of invasive fungal infections (White *et al*, 2022).
- We contributed to the new ECMM/ISHAM guidelines for diagnosing and treating rare mould infections (Hoenigl *et al*, 2021).
- A study found the fungus *Exophiala* in the cultures of around 11% of children with cystic fibrosis, but this did not seem to be associated with clinical deterioration (Mills *et al*, 2021).

Global Collaborations

Our expertise can also be extended to help centres in other countries, either involving aspergillosis or other fungal infections. This year our staff were authors on several papers from longstanding collaborations.

- A clinician visiting our department compiled a review describing the scientific literature and current healthcare gaps for histoplasmosis in Africa (Ocansey *et al*, 2022), which will help clinicians push for better access to diagnostics and treatments.
- Results were published from the APICAL trial, which measured the incidence of CPA among Indonesian patients being treated for tuberculosis and identified which patients were at greatest risk (Setiangrinum *et al*, 2021).
- Several staff visiting our centre published a study looking at how the *Aspergillus* IgG antibody test performs among Nigerian patients. They found that it would be more appropriate to use a lower cutoff (threshold value) than is recommended by the test's manufacturer, in order to avoid false negative results (Oladele *et al*, 2022).
- Our department is currently hosting a PhD student studying the prevalence and underlying causes of vulvovaginal candidiasis (VVC) among Nigerian women, which has been presented at several conferences. He has benefitted greatly

from the expertise of MRCM staff, particularly in carrying out fungal PCR, which is performed by very few laboratories.

Supporting new drug development

The NAC team has additionally secured Chief Investigator/Principal investigator roles in the following NHIR CRN portfolio and industry studies recruiting patients from our clinics:

1) Study to evaluate the Efficacy and safety of Ibrexafungerp in patients with fungal diseases that are refractory to or intolerant of standard antifungal treatment
2) The effect of PC945 on Aspergillus or Candida Lung infections in patients with asthma or chronic respiratory diseases
3) A randomized, double blind, multicentre placebo-controlled Phase 2 study t evaluate the safety, tolerability and pharmacokinetics of itraconazole administered as a dry powder for inhalation (PUR1900) in adult asthmatic patients with ABPA
4) A study to evaluate the efficacy and safety of dupilumab in participants with ABPA (LIBERTY ABPA AIRED) – reached recruitment targets

10. Patient and public engagement

The NAC CARES (Community, Awareness, Research, Education, Support) team consists of four members of staff: Graham Atherton (Team Lead), Lauren Amphlett (Patient communities, social media, MDT support), Chris Harris (NAC Manager, phone support) and Beth Bradshaw (Pan-fungal diagnostics with Mycology Reference Centre Manchester, MFIG interaction support, Medical Mycology).

The year 2021 – 2022 has seen some moderation of the impact that the COVID-19 pandemic has had on NAC patients compared with 2020-2021 but nonetheless there have continued to be several areas of concern for patients with multiple waves of the virus, continued restrictions to ‘normal life’, several vaccinations and continuing limitations to how all of NAC can communicate with patients. We have again had to be pragmatic and adaptable in order to best support NAC patients and carers.

Most consultations still take place over the phone or via videoconference rather than face-to-face, so we needed to reach out to all visiting patients and carers to inform them of our resources and support. 40-50% of this group of people state that they do not have access to the internet, but we noted that over 95% have registered a mobile phone number and we can send each text messages using Accurx services (Accurx Web services validated for us by the NHS https://www.accurx.com). Consequently, to increase awareness each patient who attends clinic is now sent a text that tells them of the support & information resources available to them as well as a weekly survey that asks them how they thought their clinic visit (face to face and virtual) went.

Most of our resources still need internet access in order to access them. More than 95% of our patients provide us with a mobile phone number that we can use to contact

them. The vast majority of UK mobile phones run on the iOS or Android software platforms (99.4% June 2021 https://www.statista.com/statistics/934440/market-share-held-by-mobile-operating-systems-in-the-united-kingdom/) so will be able to access the internet. We hope that as time goes by patients will be more highly motivated to use their internet access on their mobile phones, for example to use the new 'MyMFT' NHS patient self-management App coming in September 2022.

10.1 Patient Support Services

Telegram

Telegram.com is a private and confidential NHS-approved individual/group communication App that replaces the sadly defunct Hospify APP that we were using last year. There are three groups covering CPA/ABPA/General discussion populated by a total of 62 patients (July 2022) that are almost all NAC & NHS patients. We use Telegram to answer private & confidential questions.

Monthly NAC Zoom meetings

The NAC CARES team have been running monthly support meetings since the start of the centre. Apart from an opportunity to socialise, these meetings are intended to

- Inform
- Educate
- Provide a platform for involving& engaging our patients and carers in NAC and Manchester Fungal Infection Group (MFIG) research activities
- Give us an opportunity for the NAC team and invited external speakers to provide feedback to patients and carers on subjects that they have asked for.

We stream these meetings out live to our private Facebook group and record the content to allow them to be watched at a later date. The meetings took place face-to-face until the COVID pandemic prevented patients from attending Wythenshawe Hospital in 2020. Since that time, they have been held on Zoom and we have streamed them live to our private Facebook patient support group. The sessions are recorded by Facebook and made available through that platform. This year an average of 100-150 people have viewed these meetings or their recordings each month.

Weekly Zoom social support meetings

In the month of June 2022, 9 meetings were attended 66 times by up to 15 people. This is mostly an opportunity for social interaction and is attended repeatedly by NAC patients who find it beneficial.
Patients and carers regularly comment that his community support has made a dramatic difference to their quality of life as they feel that only people who are living through the same illness can really understand and furthermore, they can relax in their company. Aspergillosis can be a social embarrassment for some as the frequent coughing and expectoration, regularly having to cancel plans due to ill health and above all the fatigue is disruptive of their relationships with others, including family members. A meeting with fellow patients is an occasion that they will be understood and offered empathy no matter what happens.
NAC CARES team stays in the background of these meetings, only commenting when asked or if help is needed. All questions are answered until the last person leaves.

Patient Health and Wellbeing

At the heart of services offered to NAC patients and carers, and a wider UK NHS audience are activities and resources to support their health and wellbeing. Our Zoom meetings provide social interaction that has great value for such isolated patients and carers, as outlined below.

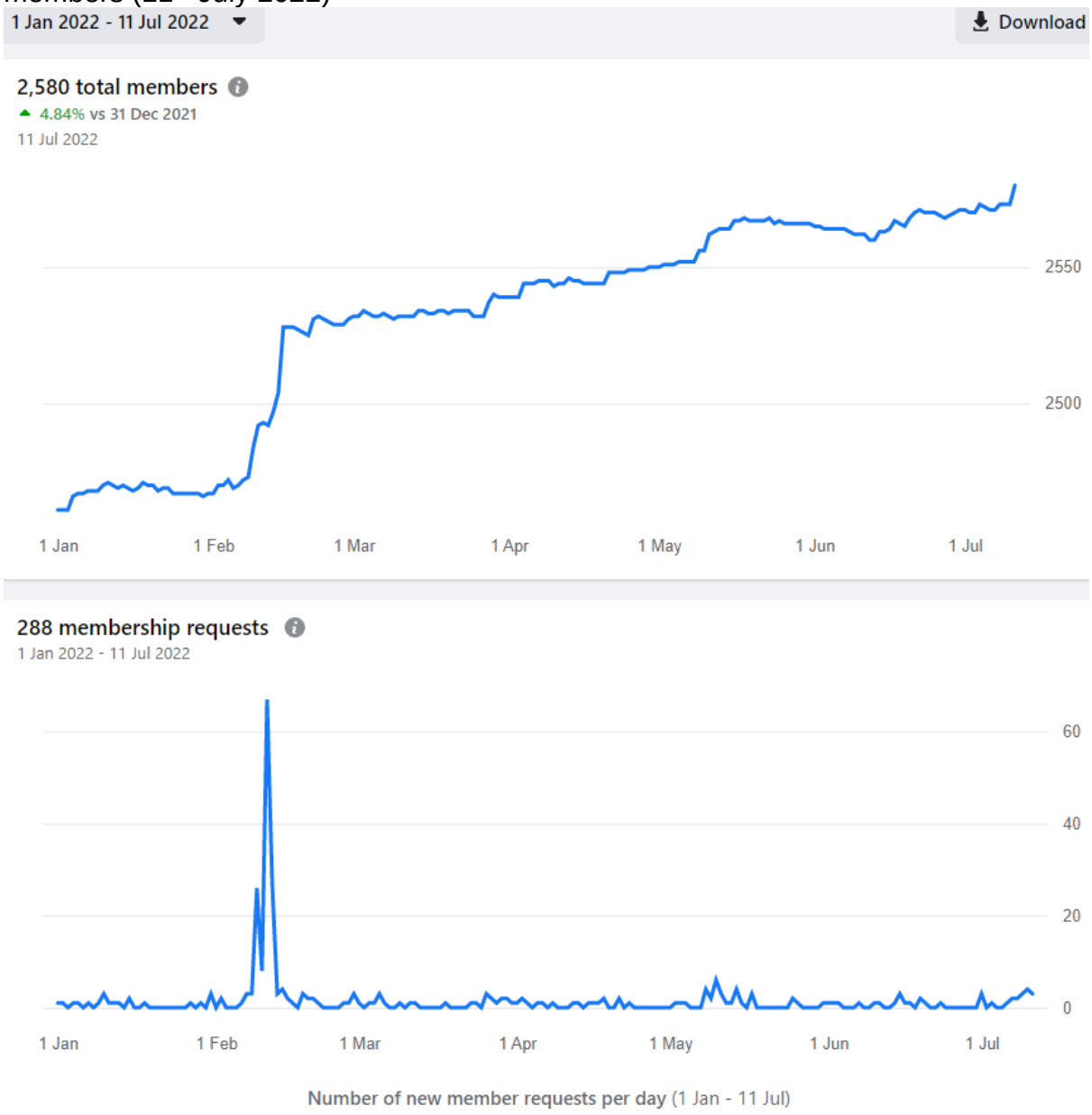
- Weekly meetings provide rapid, regular access to NAC CARES staff to provide information such as questions on keeping safe during the COVID pandemic, guidance to the correct information resources for to assess vulnerability, vaccination eligibility and many more.
- Monthly meetings provide a platform for NAC staff to give talks on a wider variety of subjects aimed at helping the 'whole person' including:
    - Quitting smoking & vaping
    - Eating well
    - The influence of the gut microbiome on lung health
    - Purchasing vacuum cleaners suitable for minimising allergies
    - Lasting power of attorney
    - Practical help with claiming benefits
    - PALS
    - Encouraging crafts/hobbies/singing
    - Recognising and reducing anxiety
    - Sitting down exercises
    - New treatments for aspergillosis/COPD/asthma/cough in development
    - New scientific approaches to learning more about lung disease
    - Progression of aspergillosis research (reports from conferences)
    - Changes in the organisation of the NHS
    - GP networks/walk-in clinics
    - COVID risk updates
    - Patient Q & A
    - Early detection of diseases neglected during the COVID pandemic eg cancer
    - Fatigue
    - Holiday travel
    - Heatwave warnings
- Aspergillosis.org often hosts articles that have resulted from a Zoom meeting discussion to provide detailed advice and guidance from reputable resources – this supports our talks and offers the information to a wider audience

Quarterly newsletter

We have remodelled the newsletter to be concentrate more on patients' needs and interests, departing from the mainly technical and research newsletter of old. It was more difficult to find relevant content for this type of publication every month, so we have switched to a quarterly format to compensate and to maintain quality standards. Readership now stands at 5472 per issue.

Facebook support groups

The National Aspergillosis Centre Support (UK) group is our largest with 2580 members (11th July 2022)



Increasing numbers of members in Facebook National Aspergillosis Centre Support (UK) in 2022.

There was a noted large spike in members following World Aspergillosis Day 2022 (1st Feb 2022 onwards).

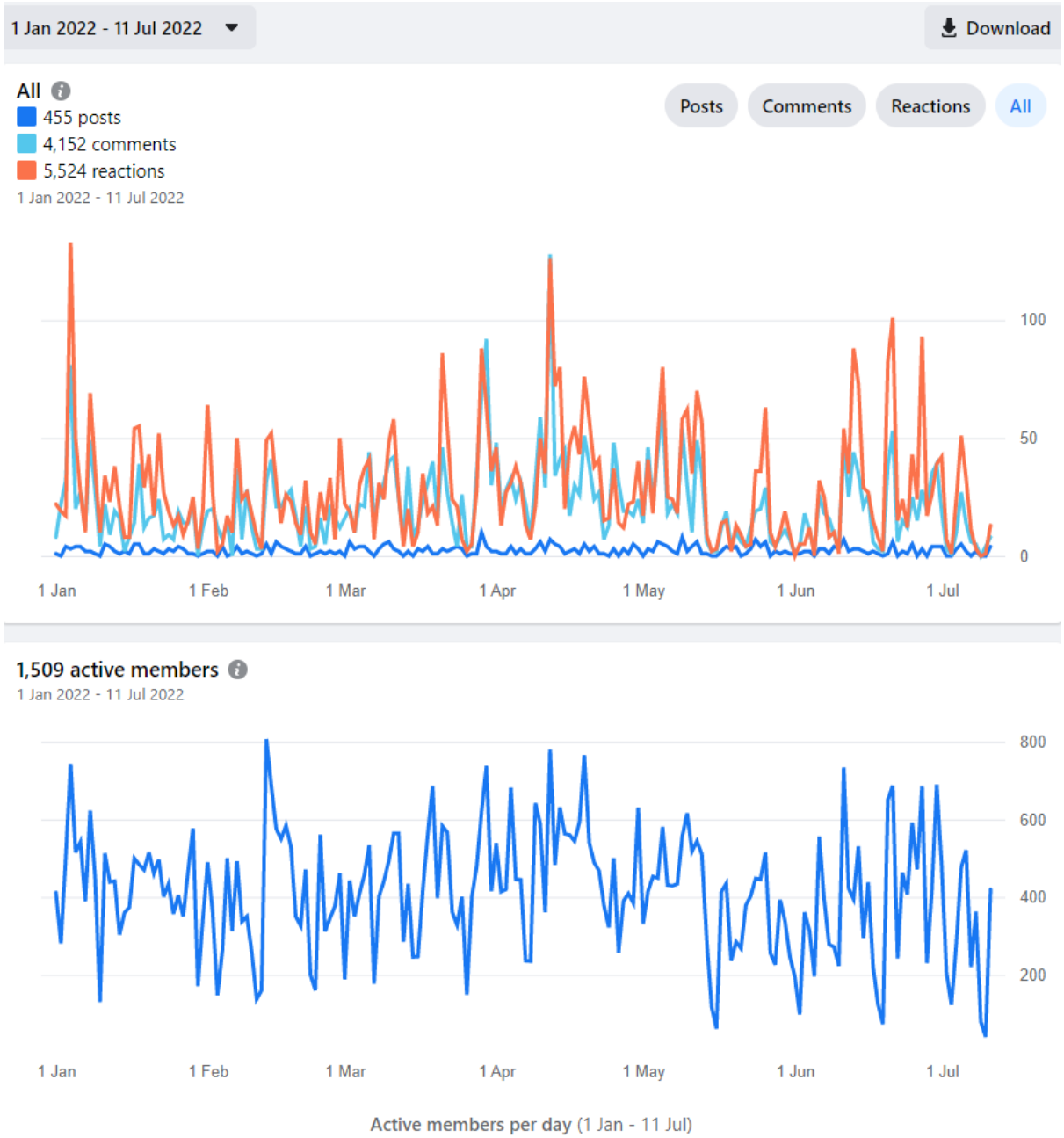


Fig 2. Facebook group activity 2022

The National Aspergillosis Centre Support Group is very active. Over the first 7 months of July in 2022 over 1500 members have been active.

Posts
The posts with the most activity in the last 28 days.

Top posts | By all

Date	Post	Reach	Engagement
20/06/2022 17:02	Just thought I'd share some good news. This awful disease does not and will not stop me from doing what I want an... Posted by	884	114
15/06/2022 22:59	Hello - have some of you already had a 5th Covid vaccination? I had 4th about 13 weeks ago and got a text... Posted by	254	40
13/06/2022 8:40	 After reading Leighs post, I too 'live with Aspergillosis'. My worst relapse lasted 5 months ending just this March. 5... Posted by	359	88
11/06/2022 13:00	What a strange journey this is. I am often told that I am taking too many steroids , too much ventolin, that I shoul... Posted by	921	104
27/06/2022 15:15	 Last week several of our staff raised awareness of aspergillosis among respiratory specialists at the British... Posted by	783	120
21/06/2022 11:59	 Hello everyone, I'm Dareen Marghlani, a Respiratory Therapist and Master's student at Imperial College Londo... Posted by	776	73
14/06/2022 3:18	I just started my Xolair infusion treatment today. I had no allergic reactions. I hope it helps with the mucus so I can... Posted by	547	35
30/06/2022 13:12	 Covid-19 Vaccination Number 5... Posted by	664	40
05/07/2022 15:31	Had an interesting - in a good way - morning at rhinology clinic at the Brompton. They do the nose part of ENT.... Posted by	559	45

Fig 3. Many posts are very popular, reaching hundreds of group members.

Since 2020 we have focussed our attention on giving priority to people entitled to claim NHS services. Although UK members still make up less than half the group, most activity with the group involved UK members as the most recent 'top ten' posts demonstrate.

10.2 Patient Feedback

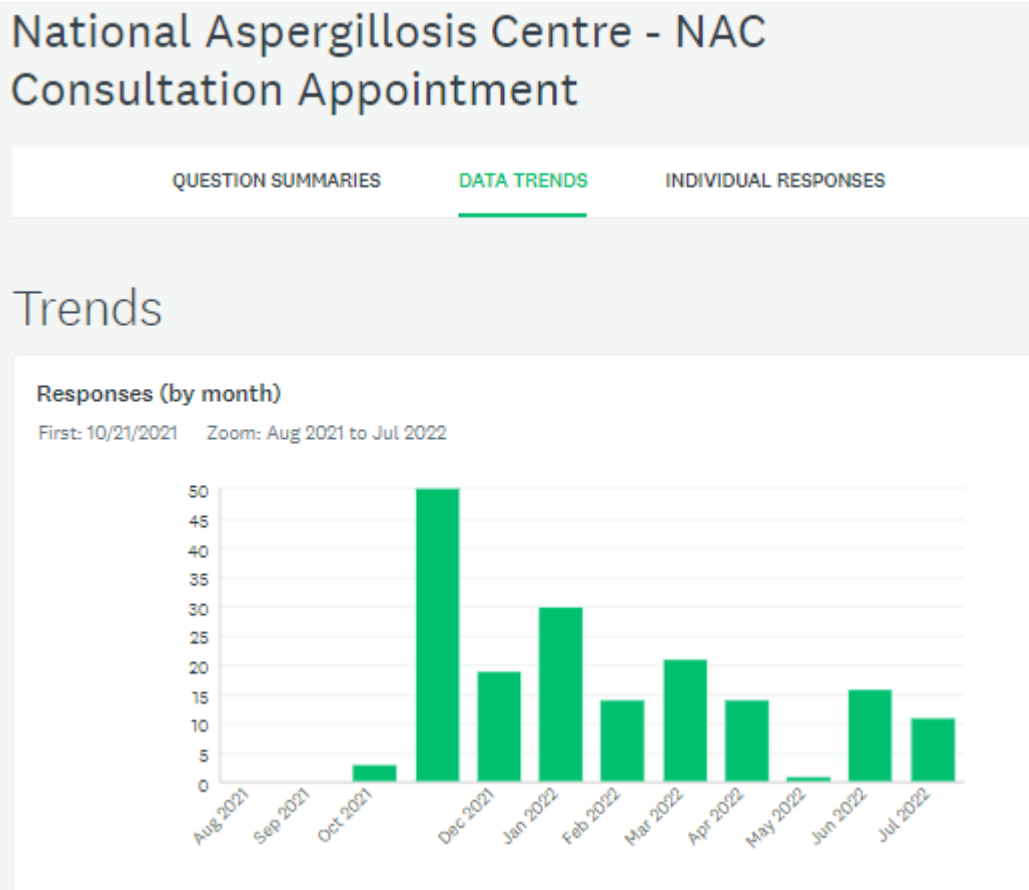
Patient feedback is key to improving our services and ensuring our patient's voices are heard and acted upon. We are always looking for new way to improve the quality and usefulness of this feedback.

Weekly patient survey

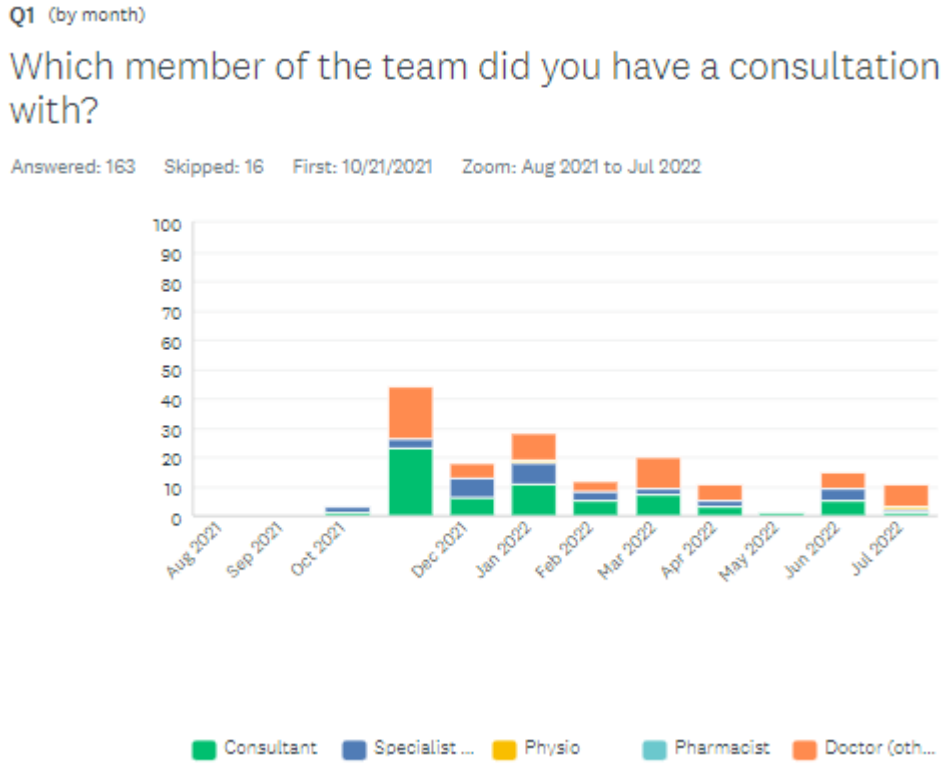
In recognition of the need to reach out to all patients for real-time, continuous feedback we have introduced a new patient feedback system that reaches >95% of all patients (offline or online) via SMS phone text.

The new service invites all patients who attend clinic (Face-to-face or virtual) to comment on how they felt their consultation went, whether it could be improved, what they thought of the individual NAC team member they saw. The link to an online survey is sent out using Accurx (accurx.com) services. All feedback is anonymous.

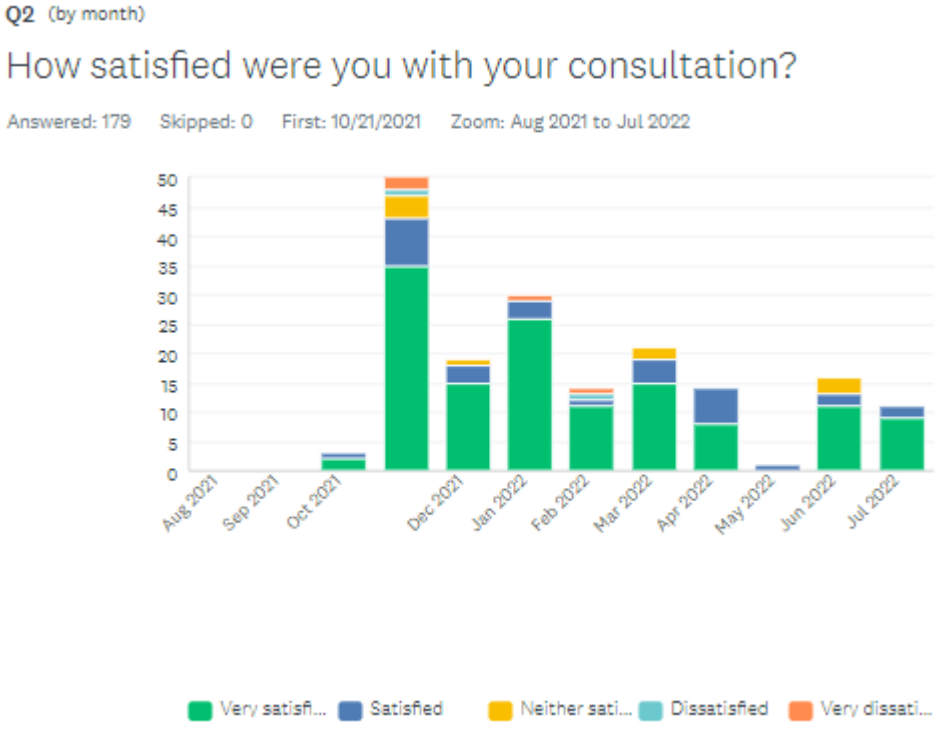
Using this service over the last 7 months of operation 179 replies have been received and analysed.



Monthly figures for consultation feedback



Monthly consultations broken down by team role



Patient satisfaction with consultation

Levels of expressed dissatisfaction are very low (6/179 (3%) overall) but where it is raised the relevant team lead is informed and a solution discussed. This survey also allows for comments that are often helpful. Of the six comments that expressed dissatisfaction, four related to difficulties in communication when appointments were

cancelled and two related to the communication skills of the doctors concerned (patients did not feel they were adequately listened to)

Annual patient survey

The NAC Annual Patients Survey is run for one month each year and aims to get patients opinions on the whole service, its interaction with patients and the resources it provides. The purpose is to identify any weaknesses in the service or unmet needs so that we can improve and strengthen the service.

This survey was originally given out in paper format to all patients who visited a NAC clinic each week but of course this became impossible during the COVID pandemic as there have been far fewer face-to-face consultations. In 2021 the survey was posted out in paper format with an option to return it online, but that was very laborious and time consuming. As NAC clinics remain only partially face-to-face, we have again offered this survey in a variety of ways to try and ensure that every patient is given an opportunity to complete it.

For the first time, we had access to Accurx internet services that allowed us to send all patients a text message offering the survey. In practice, more than 95% of all of our patients were able to receive text messages so we opted to use this method rather than attempting to send out paper copies to all patients as we did last year. Links to the survey were also provided at the end of all video consults.

The questionnaire was offered using a web application that allowed any patients with access to the internet via laptop/tablet/phone to complete it, and we offered to take entries over the phone for those with minimal web access.

The patient's survey was offered from April 22nd to June 27th – targeting a total of 351 patients. Of those, 40 patients (11.4%) responded and completed a survey. This is more that we received online in 2021 (33) but lower overall (62 questionnaires were completed in 2021) due to the number of paper surveys returned by post (29).

In 2021 many patients stated that the reason they had not visited the website was due to lack of access to the internet (9/19 47%). Clearly, those people would not have access to the survey via the internet in 2022 though we did offer to complete the survey for them over the phone. We cannot use an online survey to reach people who have no access to the internet and offering phone contact to complete the survey has not worked as no-one made contact over the phone. The app MyMFT may encourage people to get access to the internet but there will be people who have no access for some time yet. Instead, we need to contact more patients when they attend face-to-face appointments at clinic and post out paper versions for those groups identified with no internet access.

<u>Survey Highlights</u>

Below is a summary of the main points for change 2021-2022 (NOTE that some questions were new this year so no direct comparison with last year can be made). The full survey results can be seen in Appendix 8.

- Video consultations have been less well received compared with 2020-2021 with more than three times higher dissatisfaction rates. There is frustration around the software not working well and a few were unaware of the option to use videoconference. The software will be changing imminently as our Electronic patient record changes to 'HIVE'. We will re-monitor this next year.

- When patients were asked which type of appointment they preferred there were no clear preferences with roughly equal numbers wanting to be contacted face-to-face/videoconference/phone/mixture. We plan to continue to provide a mix of options for each patient.
- Approval of staff courtesy was down slightly more for nurses (though still >90%) possibly reflecting the greater demands made on all staff in the last 12 months.
- Approval of staff communication & care was high (>90%) for all staff groups.
- Approval of communication for clinic appointments was high (88%) but there were several comments suggesting improvements that could be made (see Q5 in Appendix 8).
- Information leaflets have maintained high approval rates (100%)
- There has been a reduction in the number of patients recalling being told about symptoms to be aware at home.
- Hearing about palliative care is still of interest to 33%, one patient requested that more information should be available
- Feedback for our postal blood and sputum service has improved. There are lots of positive comments on these services (see Q14 & Q15 in Appendix 8). Direct access for patients to their own results will become available in MyMFT.
- NAC website aspergillosis.org was seen by 40% of patients asked, and 100% approval.
- Interest in NAC Zoom monthly meetings continues to climb (7.5%)
- There was a large drop in patient numbers who are members of our Facebook support group (43% - 18%) and weekly Zoom meetings (41% - 23%)
- There is a lot of interest (40%) in using our secure and confidential patient groups in Telegram.com

General comments about the NAC services from patients completing the survey:

23. Do you have any other general comments about the NAC service?

23. Do you have any other general comments about the NAC service?
Could this service help me with my benefits
Everyone is very helpful and friendly and I think that goes along way. God bless you all
Everything's been absolutely fine
First time used today and I feel reassured and confident that the process is well designed and well staffed.
Great hospital and great service.
I have never been to a hospital where they don't treat you like a patient they treat you as a person and they don't rush you they make you feel very welcome
I'm grateful for the improvement in my condition
It has been very helpful with caring staff. Really appreciate it
It is a great service with fantastic people!
My contact has been with specialist nurses who are excellent. Thank you

No
No I'm very grateful to everyone that helps me thank you all
None.
Not at the moment
Nothing to add except every one Ive met are keen to help or look up things for you or send video links.
Probably be discharged soon
Very helpful, very professional and caring

NAC response to the annual survey
We have developed a set of actions in response to this survey:

Action point A: 19/40 (48%) of patients had been told about symptoms to be aware of at home (2021 76%) which is quite a large drop from the previous year.

- Response: NAC needs to ensure all patients are informed about symptoms to be aware of at home, due to medication or illness – CARES team will update our patient information leaflets to be distributed via clinic, post and MyMFT.

Action point B: 13/40 (33%) stated an interest in hearing more about palliative care (2021 46%) which is a drop on 2021 figures but still a large increase on earlier years (2020 & 2019 10%).

- Response: CARES team to design new leaflet for distribution via clinic, post and MyMFT

Action point C: When asked if there was a reason why they had not visited the website there were two types of response:

1. People who had never heard of the website (8/14, 57%)
2. People were not interested in reading further information (3/14, 21%)

- Response: CARES team to promote aspergillosis.org to patients by leaflets/MyMFT

Action points D/E/F/G: Comments tell us that many patients did not know about the Zoom monthly meetings/Zoom social meetings/Facebook groups/Telegram

- Response: This implies that more might attend our Zoom meetings/Groups if they were more widely known about. CARES team to promote more to patients by text/leaflet/face-to-face/MyMFT.

11 Raising public awareness and educational outreach

Social Media Impact report

As a national leader in the clinical management of chronic pulmonary aspergillosis (CPA), the need to communicate and engage well with our patients, their carers, the public, clinicians, researchers and other key stakeholders is essential for the provision of long-term care for patients with the condition.
In November 2020, we employed a PR & Communications Specialist to support the delivery of NAC communications.
An important element of this role has been the development of social media channels, which has focused on raising the profile of the National Aspergillosis Centre, increasing awareness of aspergillosis, driving engagement, and supporting broader health promotion campaigns through:

- Promotion of the National Aspergillosis centre as a place to be treated, to learn and to work
- Dissemination of educational materials tailored to clinicians, researchers, patients, and carers
- Curation of content related to NHS and Public Health England campaigns

As with all providers of NHS services, there has been a continued need throughout the pandemic to address the challenges associated with communication and engagement. The Covid-19 pandemic has continued to shape the landscape of communication, and social media has remained a primary source of information. This report looks at the impact of activities undertaken across all social media platforms.

Social media platforms utilised by the National Aspergillosis Centre

Channel	Audience	Content
Twitter	• Patients • Carers • Clinicians (Drs/Nurses/Physiotherapists) • Fungal research community • Media • Academia	• Information about aspergillosis • NAC news • Job opportunities • Achievements • Research • Useful third-party information (for example, mental health day, information about Covid19) • Information about NAC and the service • Interest pieces • Links to more detailed content on other platforms
LinkedIn NAC Page	• Clinicians (Drs/Nurses/Physiotherapists) • Fungal research community • Academia	• NAC news • Information about NAC and its services • Research • Interest pieces (professional focus) • Blogs • Job opportunities • News from the wider community • Press releases
Facebook NAC	• Patients • Carers	• Information about aspergillosis • NAC news • Achievements • Useful third-party information (for example, mental health day, information about Covid19.) • Information about NAC and the service • Patient stories
Facebook Aspergillosis Support	• Patients • Carers	• NAC news • Advice/support • Useful third-party information (for example, mental health day, information about Covid19)

Channel analytics July 2021 – July 2022

Channel	Followers / Growth Growth across social media platforms is reported in the table below over a ten-month period. The growth of our platforms is important because it will allow us to extend our reach further and engage with key stakeholders in the table above.	Total engagement Engagement is a measure of participation / interaction with content. This can include: • Liking • Sharing • Commenting • Opening a link within the post	Total reach / impressions This is the potential size of the audience reached when content appears on a social media feed, regardless of if the content is interacted with.
Twitter	July 2021 – 2543 July 2022 - 3300 Growth +30%	5218	2.1million
LinkedIn NAC Page	July 2021 – 1291 July 2022 – 1736 Growth +34%	5858	93K
Facebook NAC	July 2021- 435 July 2022 - 601 Growth +38%	-	16K

World Aspergillosis Day (WAD 2022)

February 1st has been World Aspergillosis Day for six years, each year attempting to raise awareness of diseases caused by *aspergillus (*see *WorldAspergillosisDay.org for full details)*.

This year the UK National Aspergillosis Centre in Manchester held a day of short seminars online on Zoom. You can find the program below:

10am Welcome

Specialised services at the National Aspergillosis Centre (NAC), Manchester

10:10
How the National Aspergillosis Centre came to be.
Chris Harris, NAC Manager
10:25
Who gets aspergillosis?
Caroline Baxter, NAC Clinical Lead
10:40
How do we detect aspergillosis?
Lilly Novak-Frazer, MRCM (diagnostics)

10:55
How do we treat aspergillosis?
Chris Kosmidis, NAC Consultant
11:10
Are antifungal drugs complicated to use?
Fiona Lynch, Specialist Pharmacist
11.25
Getting treatment to everyone that needs it.
Liz Wilson, Out-patient parenteral antimicrobial therapy (OPAT) service
11:40 – 12:10
Helping patients live with aspergillosis.
Phil Langridge, Specialist Aspergillosis Physiotherapist
Jenny White, Aspergillosis Specialist Nurse

12:10 end of first half

13:00
Patient Panel Stories: Living with aspergillosis
Questions?

14:00
MFIG research in Manchester
Angela Brennan

14:30
MRC Centre for Medical Mycology, Exeter

15:00
European Lung Foundation
Advocating for patients, involving patients in research across Europe

Each talk was recorded and is available to watch at:
https://www.aspergillosisday.org/WAD2022/national-aspergillosis-centre-seminar-series/

There have been 1277 views of this page and the video's (a set of 16 in all) have been viewed 1353 times so far. Many of these videos were planned to be re-used multiple times as an excellent resource for patients.

There were 181 people booking to watch the day's events and asked each to complete a survey at the end of the day to assess how well we have met patient's needs (Appendix 9 WAD 2022 Survey).

There was also an extensive social media campaign, the figures for which are included in the social media report above (2.1 million tweets, 93,000 LinkedIn and 16,000 engagements on Facebook).

Aspergillosis Patients and Carers Website (aspergillosis.org)

This website focuses on the support of patients and carers, in particular providing information on Aspergillosis and its treatment, latest news, fundraising, educational videos and links to support.
https://aspergillosis.org

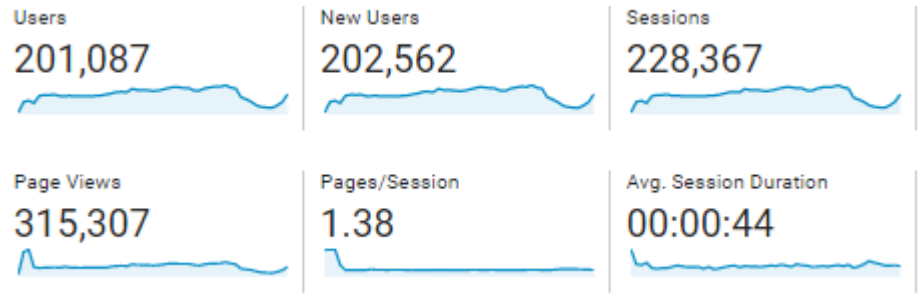


Fig 4. Website usage figures for 2021-2022 (12 months) show a steadily increasing numbers of users and sessions with over 200 000 users over the 12 month period.

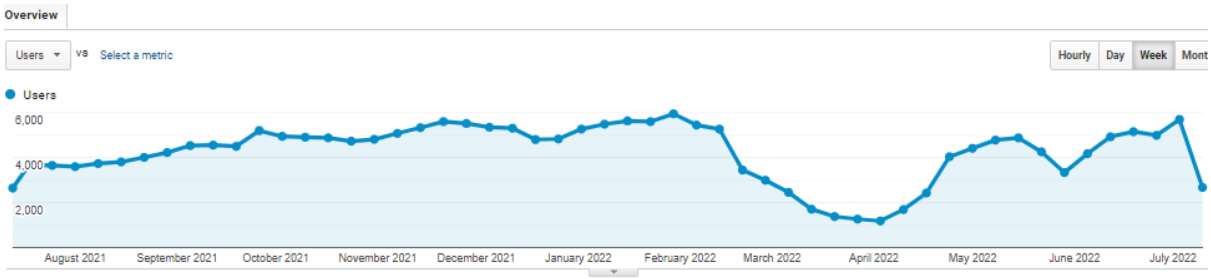


Fig 5. The dip in users that took place in March-April 2022 is due to our change of provider for translations. The original provider could not provide translations for most middle eastern languages commonly spoken in the UK that, taken together make up 10% of all spoken language in the UK (see 2011 census figures https://en.wikipedia.org/wiki/Languages_of_the_United_Kingdom) so we switched to Google translate software. The numbers of users have now recovered (July 2022).
Other aspects of accessibility that were updated in 2021-2022 were:

- Enhanced contrast and text size for the visually impaired
- Usability on mobile platforms (mobile phones account for 75% of browsing sessions)
- Building in support for Browse Aloud assistance for the blind

In the Patients annual survey 2022 40% of all NAC patients had visited aspergillosis.org. 100% were satisfied or very satisfied with the website content.

Website mft.nhs.uk

The CARES team gained access to edit entries for NAC in the University of Manchester NHS FT (MFT) website in 2021 and have regularly updated our entries and developed content. This is the major route for outside users to access important

information about NAC – e.g., referral criteria. The MFT website provided 440000 page views in the 30 days up to 13th July 2022.

This website also provided an opportunity to react to a comment made in patient feedback that patients were finding it more difficult to recognise new members of staff as they were no longer able to have face-to-face visits to clinic. The NAC section of the MFT website now hosts names and photos of most members of staff who work in a patient facing role.

Attending UK conferences

As part of our efforts to increase awareness of NAC and aspergillosis in the medical community, the CARES team attend relevant UK conferences to deliver posters and a range of leaflets tailored to the particular community attending each conference. In 2022 Beth Bradshaw has attended the NHS Radiology Conference and the British Thoracic Society Conference.

Research

The CARES team supports NAC researchers by promoting a very positive attitude to aspergillosis research and in particular research done at NAC. Groups of patients that have stated an interest in volunteering to help with research by helping with documentation, providing opinions during project development and volunteering for patient representation are maintained. We often help interpret and simplify some of the more complex research details to both help understanding and enhance the relevance of a project to patients' lives. In 2022 we will be providing patient representation for the British Thoracic Society Clinical Statement on pulmonary aspergillosis.

Communities

Lauren Amphlett has worked tirelessly to develop relevant communities via social media that we can use as targeted audiences for awareness, education and to assist research and clinical staff.

- Linkedin

NAC has run a dedicated page in LinkedIn for some time now for the purpose of engaging professional audiences that we can reach out to, increasing awareness of aspergillosis and NAC throughout the medical and research communities in the UK and abroad.

Fig 6. LinkedIn NAC page follower demographics showing professional role (top 10).

The demographics of those professional groups that actively follow NAC on Linkedin shows the top three groups relate to research, healthcare and education (57% of the total). These are all sectors we target with our content as they are highly relevant to NAC aims. For example, these are all professional groups that will be responsive to our promotional work on World Aspergillosis Day (Feb 1st - see attached report).
The number of followers of the NAC LinkedIn community has increased over the last 12 months by 416 to 1736 (511% increase).
The Mycology Reference Centre Manchester (mrcm.org) LinkedIn page is also supported by the CARES team and again we see great engagement of professional groups within research, healthcare and education (56% in total). The MRCM LinkedIn page has 1822 followers of which 630 joined in the last 12 months (473% increase). Followers are predominantly based in the UK but the top ten includes India, New York, Toronto and Brazil.

- Twitter

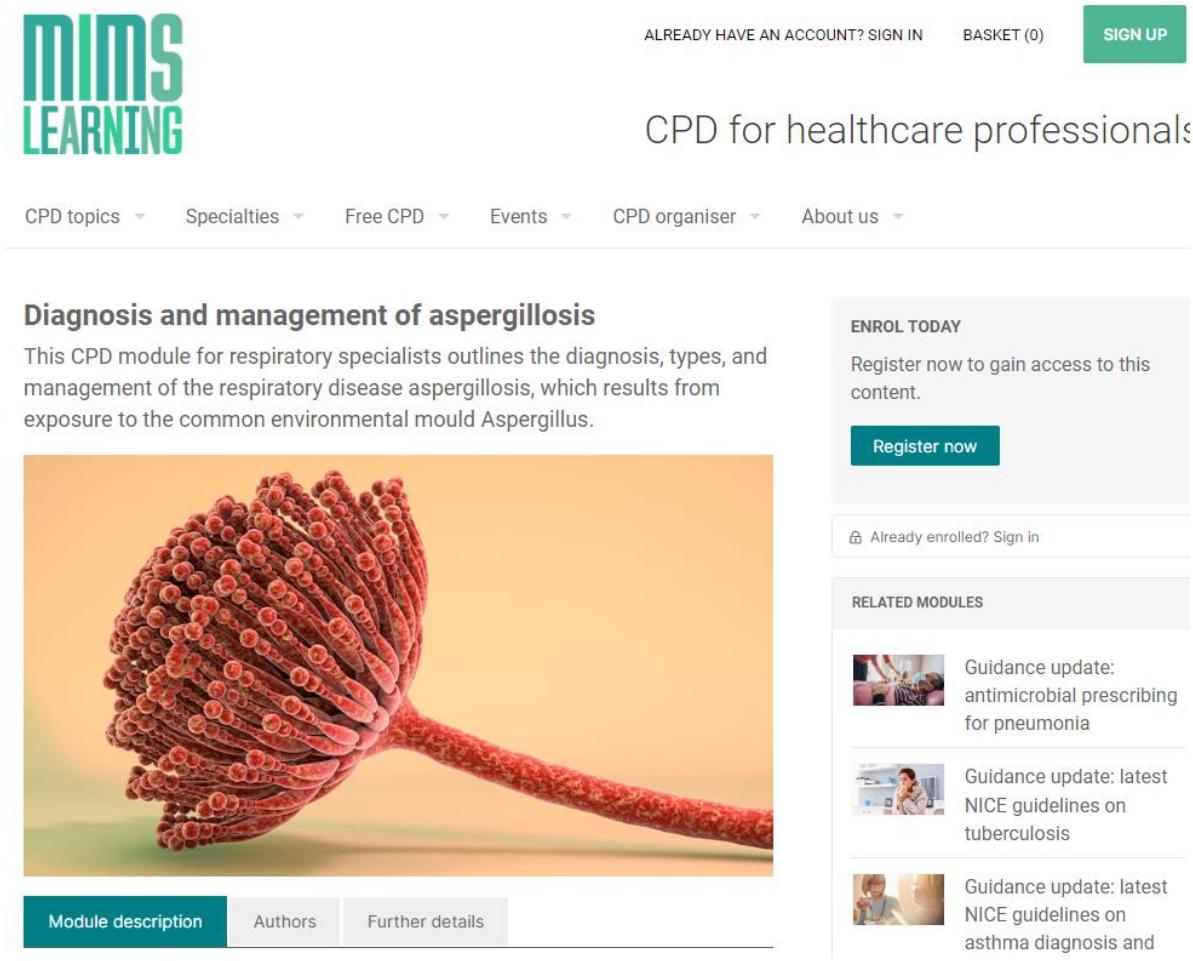
This is an important platform as it hosts a much broader range of audiences compared with LinkedIn, including patients, carers, researchers, journalists – so there is a lot of potential for linking these audiences with cross-cutting content. In particular, we see a lot of comments from researchers on areas of common interest to patients – sometimes these may be on research projects that NAC patients have volunteered for

so act as a type of informal feedback. We can also promote patients comments/video's back to researchers.
Twitter followers of NAC's twitter page have increased from 2543 to 3300 over the last 12 months, an increase of 30%. Reach and engagement are also useful guides to how many people we manage to put in front of our content – in the last 12 months we have reached 2.1 million people with our content and of those 5218 have engaged with it.
Lauren Amphlett's Social media impact report 2021-2022 goes into more detail of our promotional activities and how well we have managed to reach and engage our audiences is attached to this report.

Education
The NAC team participates in regular lectures and teaching across MFT to raise awareness of this disease for our doctors, nurses and AHPs of the future. The NAC team has also continued to deliver regular lectures via videoconferencing across the country to raise awareness of Aspergillosis amongst clinicians

- British Thoracic Society Bronchiectasis Short Course May 2021 – 'Aspergillus in the Bronchiectasis Clinic' – A series of case presentations
- Greater Manchester NIHR Virtual Study Day – Respiratory Infections June 2021
- Midlands Thoracic Society Oct 2021
- North West SpR Teaching Programme Oct 2021
- All Wales Respiratory SpR Spring Training Week: Infection Day April 2022
- British Thoracic Society Summer Meeting June 2022

The CARES team and NAC fellows with NAC consultant Chris Kosmidis have partnered with MIMS Learning (mimslearning.co.uk) to deliver a CPD course entitled the 'Diagnosis and management of aspergillosis' to primary-level medical professionals (https://www.mimslearning.co.uk/courses/aspergillosis). This course has been offered since January 2022. We have asked to feedback from MIMS to tell us how many may have taken the course so far but have not yet received any.

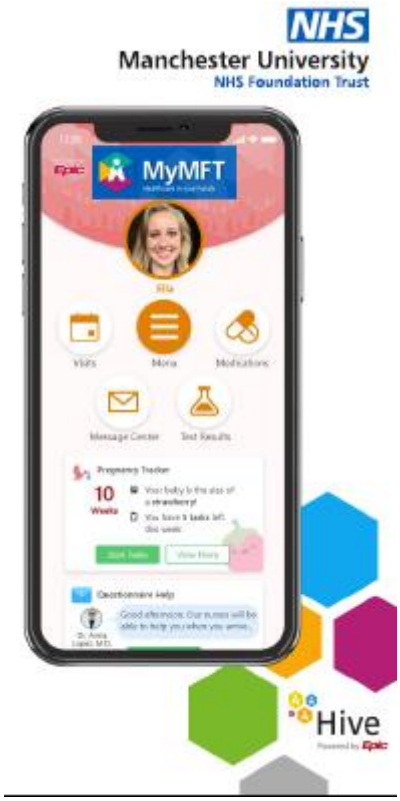


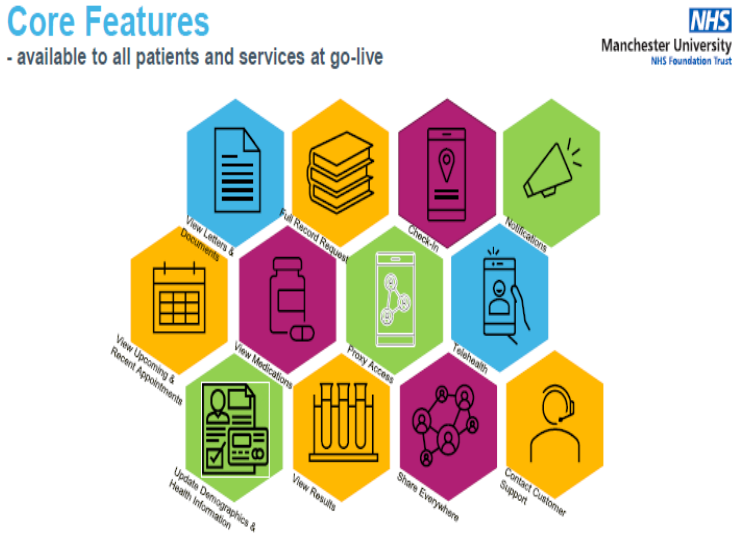
This course is something that has long been asked for by our patient communities as a way for their GP and other medical professionals to get better informed about aspergillosis.

13. Future Service Developments

The following developments are planned for 2021/2022

- Preparation for Hive (powered by EPIC)
  Hive is our new Trust innovative digital healthcare solution. Hive will bring our patient information into one easily accessible place to make services more effective. Our team has undergone significant preparation and training to prior the launch of this electronic patient record in September 2022 at MFT. Alongside this comes the launch of the patient facing portal 'MyMFT'. This will significantly change the way we communicate with our patients, but we will have to ensure it does not lead the digital inequality for those who do not access online services.





- Embed our new National access MDT
  We aim to monitor our activity and the benefits of this new service. We will report the geographical reach as we begin to promote this service.
- Service re-specification with NHSE
  We plan to continue our work with NHSE to re-develop the NAC service specification to ensure the service delivers the best possible patient care and experience without regional variation.
- Patient Feedback
  We aim to continue to improve patient feedback building on the platforms currently in use. We want to be able to reach a wider and more representative cohort of patients and allow feedback to be done continually, in real-time, rather than retrospectively annually.

- Palliative Care
  We wish to form partnerships with our local palliative care teams to enhance end of life care and delivery of the gold standards framework for patients in our service.
- Implementation of an annual patient review process
  We have not managed to achieve this over the last year but wish to keep it at the forefront of our clinical development. We are aiming to introduce an annual review process for all patients. Patient management will be assessed by individual members of the MDT team including a doctor, specialist nurse, physiotherapist and pharmacist. Cases will be subsequently discussed with the wider MDT to ensure optimal clinical care, antifungal stewardship and communication with patient GPs and secondary care consultants.

Appendix 1 Categorisation (Banding) of CPA disease complexity

Stage 1

- Ambulant and independent
- No evidence of antifungal resistance
- No treatment or treatment with itraconazole capsules

Stage 2

- Significant impairment of respiratory function, sufficient to impair activities of daily living, but ambulant
  and/or
- Concurrent anti-mycobacterial treatment
  and/or
- Failed or developed toxicity to itraconazole capsules
  and
- No evidence of azole antifungal resistance

Stage 3

- Antifungal azole resistance documented
  and/or
- Long term nebulised or IV antibiotic treatment required (bronchiectasis, Pseudomonas colonisation)
  and/or
- Wheelchair bound
  and/or
- HIV infected
  and/or
- Severe hepatic or renal disease

Appendix 2 New Patient Audit

NATIONAL ASPERGILLOSIS CENTRE

New patient audit - Nov 2020– March 2021

MONTH	DATE REFERRED	Priority	APPOINTMENT DATE	WAITING TIME -weeks	POSTCODE	AREA	CPA Band	Antifungal at 1st visit	Antifungal at 3 months	1-Year Clinical Outcome	Comments
NOVEMBER	08/10/2020	Routine	06/11/2020	4	EH55	Scotland	2	None	None	Died 08/04/21	Multiple prior antifungals and surgery
	12/10/2020	Routine	13/11/2020	4	FY1	Blackpool	1	Itra	Itra	Improved	IgG improved, weight/SQRQ stable, CT improved
	12/10/2020	Routine	13/11/2020	4	FK1	Scotland	2	Vori	Vori	Improved	CT improved, IgG improved, SGRQ improved
	09/11/2020	Routine	27/11/2020	2	NP13	Wales	2	Vori	Vori	Stable	CT stable, IgG improved
	Late registration	Routine	26/07/2017		BN11	West Sussex	1	Itra	Itra	Stable	CT stable, IgG stable
DECEMBER	05/11/2020	Routine	04/12/2020	4	CV11	Warwickshire	2	Vori	Vori	Improved	CT stable, IgG improved, Weight improved
	29/10/2020	Routine	04/12/2020	5	DE73	Derby	2	Vori	Vori	Stable	CT stable, IgG improved, SGRQ stable
	09/11/2020	Routine	11/12/2020	5	HD3	Huddersfield	1	Itra	Itra	Deteriorated	CT worse (switch Posa) Iimproved SGRQ, and weight,
	15/10/2020	Routine	18/12/2020	9	WN8	Wigan	1	None	None	Improved	CT improved, SGRQ/Weight improved
JANUARY	24/11/2020	Routine	08/01/2021	6	BB11	Burnley	2	Vori	Vori	Improved	CT improved, IgG improved, weight improved
	04/01/2021	not stated	15/01/2021	1	M3	Manchester	2	Vori	None	Stable	CT stable, patent declined on-going follow-up
	08/12/2020	Routine	22/01/2021	6	SA9	Wales	1	Itra	Vori	Died 02/07/21	Pneumothorax due to Langherans Cell Histiocytosis
FEBRUARY	18/02/2021	Urgent	26/02/2021	1	M13	Manchester	2	Vori	Vori	Improved	CT improved, IgG improved, SGRQ/weight improved
	30/12/2020	Routine	05/02/2021	5	PR6	Preston	1	None	Vori	Improved	CT improved, IgG improved, SGRQ stable, weight improved
	14/12/2020	Routine	15/01/2021	4	DN14	West Yorkshire	2	Vori	Vori	Improved	CT stable, IgG improved, SGRQ/weight improved
MARCH	26/02/2021	Routine	19/03/2021	3	BD14	Bradford	2	Vori	Vori	Improved	Lobectomy June 2021

Notes

Transition patients are those that were under NAC service with a non-CPA aspergillus diagnosis that transformed into CPA

Late registration refers to patients who has a complex diagnostic pathway or who were inadvertently not entered into monthly figures at diagnosis.

New patient audit - April 2021– March 2022

MONTH	DATE REFERRED	Priority	APPOINTMENT DATE	WAITING TIME -weeks	POSTCODE	AREA	Band	Antifungal at 1st visit	Antifungal at 3 months	Clinical Outcome	Comments
APRIL	01/03/2021	Routine	09/04/2021	5	BL1	Bolton	2	Vori		Died 6/5/21	Severe COPD
	04/03/2021	Routine	16/04/2021	6	M24	Manchester	1	None	None	Improved	CT/IgG/weight/SGRQ improving
	02/03/2021	Routine	16/04/2021	6	M26	Manchester	1	None	Vori	Died 29/12/21	PHT and PE, CPA was improving (IgG and CT)
	17/09/2020	Routine	09/10/2020	3	M25	Manchester	2	Isavu	Isavu	Improved	Lobectomy
MAY	23/04/2021	Soon	14/05/2021	3	M41	Manchester	2	Vori		Died 19/07/21	Severe COPD and heart disease
	14/04/2021	Routine	14/05/2021	4	BL4	Bolton	2	Vori	Vori	Died 17/11/21	Bedbound due to sarcoid fibrosis. IgG had improved, was due CT Dec
	21/08/2020	Late registration	13/11/2020	0	B8	Birmingham	2	Vori	Vori	Died 11/09/21	Resp failure due to cocaine use
	03/02/2021	Routine	19/03/2021	6	BD17	Bradford	1	Itra	Itra	Improved	IgG improved, CT improved
JUNE	24/05/2020	Routine	25/06/2021	4	ME12	Kent	2	None	Posa	Improved	CT/IgG/SGRQ improved, weight stable
	30/04/2021	Routine	11/06/2021	6	CV23	Rugby	1	None	None	Stable	clinically stable, awaiting repeat CT
	01/06/2021	Urgent	18/06/2021	3	WR5	Worcester	1	Itra	Vori	Stable	CXR stable, IgG stable, low SGRQ
	30/04/2021	Routine	18/06/2021	7	BD13	Bradford	2	Vori	Vori	Died 02/12/21	CPA improving, death unrelated
	30/03/2021	Routine	07/05/2021	5	M33	Manchester	1	None	(patient dec	Died 14/02/22	Severe COPD
	06/05/2021	Routine	25/06/2021	7	M18	Manchester	2	Vori	None	Improved	CT improved, IgG stable, weight improved
	15/02/2021	Routine	28/05/2021	14	BL1	Bolton	1	None	None	Improved	Pt re-scheduled new appointments x3, CT improved, SGRQ stable. DFS Dec 2021
	24/03/2021	Routine	07/05/2021	6	L4	Liverpool	1	None	Vori	Improved	CT improved, IgG improving, weight/SGRQ deteriorating (heart failure)
	08/04/2021	Routine	14/05/2021	5	SK8	Stockport	1	None	None	Stable	CT stable. Clinical detrioration due to brain haemorrhage
JULY	07/07/2021	Routine	23/07/2021	2	OL3	Oldham	1	None	Itra	Deteriorated	CT worse, IgG and symptoms improved. Surgical referral and change to vori
	25/06/2021	Routine	30/07/2021	5	WN6	Wigan	2	Isavu		Died 08/08/21	Metastatic pancreatic adenocarcinoma
	20/05/2021	Routine	25/06/2021	5	BT14	N.Ireland	2	None	Isavu	Improved	Surgical resection Oct 2021
	06/05/2021	Routine	04/06/2021	4	DL7	North Yorkshire	2	Posa	Posa	Improved	Surgical resection Nov 2021
	24/03/2021	Routine	30/04/2021	5	SK14	Hyde	1	None	None	Stable	CT stable, clinically stable
	17/05/2021	Routine	25/06/2021	5	DL5	County Durham	2	Vori	Vori	Improved	CT improved, IgG/Weight/SGRQ improved
AUGUST	02/07/2021	Routine	23/07/2021	3	LL34	Wales	2	Vori	Vori	Improved	CT improved, IgG improved, weight improved, SGRQ deteriorating slightly
	17/01/2020	Routine	31/01/2020	2	BL3	Bolton	1	None	None	Stable	CT and IgG stable, SGRQ worse due to pneumonia and PE
	06/05/2021	Routine	28/05/2021	3	DL9	North Yorkshire	2	Vori	Vori	Improved	CT and IgG improved, weight and SGRQ improved
SEPTEMBER	19/08/2021	ward referral		0	M33	Manchester	2	Posa		Died 21/09/21	Lung cancer
	20/08/2021	Routine	17/09/2021	4	SK2	Stockport	2	Vori	None	Improved	Improved CT and IgG. DFS as left country
	17/02/2021	Routine	12/03/2021	3	WN2	Wigan	1	None	None	Improved	Lobectomy June 2022, IgG improved
	08/04/2021	Routine	30/04/2021	3	SK6	Stockport	1	None	None	Improved	Surgical resection Mar 2021, DFS Oct 2021 as CT resolution
	09/03/2021	Routine	16/04/2021	5	TF10	Shropshire	1	Itra	None	Stable	CT stable, IgG stable

OCTOBER	15/09/2021	Routine	29/10/2021	6	DE15	Staffordshire	2	Vori	Vori	Improved	CT stable, IgG improved, symptoms improved
	16/08/2021	Routine	10/09/2021	4	CM2	Essex	2	Vori	None	Improved	CT improved, IgG improved
	05/08/2021	Routine	03/09/2021	4	CF31	Wales	2	Posa	None	Stable	CT stable, IgG stable, symptoms stable
NOVEMBER	28/09/2021	ward referral		0	M22	Manchester	2	Vori	Isavu	Stable	Complex concurrent lung cancer, IgG stable
	04/11/2021	Routine	30/11/2021	4	N17	London	2	Vori	Posa	Improved	CT improved, IgG increased, symptoms improved
	01/04/2020	Transition	10/07/2020	0	WA8	Widnes	1	None	None	Improved	CT improving, background ABPA, symptoms/weight improved
DECEMBER	21/10/2021	Routine	17/12/2021	8	DN33	Grimsby	2	Posa	Posa	f/u July 2022	
	12/11/2021	Routine	10/12/2021	4	BL8	Bury	1	None		Died 28/12/21	Death not related to CPA. Severe COPD and MAI infection
	15/11/2021	Routine	31/12/2021	6	LE67	Leicester	2	None	Posa	Improved	CT improved, IgG improved, symptoms stable
JANUARY	09/12/2021	Routine	07/01/2022	4	DH7	Durham	1	Itra		f/u April 22	
	20/12/2021	Routine	14/01/2022	4	DY12	Worcestershire	2	Vori		f/u April 22	
	10/12/2021	Routine	21/01/2022	7	PE24	Skegness	2	Isavu	Isavu	Deteriorated	CT worse, IgG worse, SGRQ worse - change to Vori
		Transition	29/03/2018	0	BL9	Bury	2	None	Vori	Improved	SAIA became CPA nodule
FEBRUARY	06/01/2022	ward referral		0	M20	Manchester	2	Vori	None	Died 7/3/22	Lung cancer
	17/01/2022	Routine	21/02/2022	5	YO23	York	1	None	None	Stable	DFS Feb 2022 as no treatment required. On chemo
	26/10/2021	Late registration	03/12/2021	6	BB6	Blackburn	1	Itra	None	Died 13/3/22	Severe COPD, abdominal maligancy
MARCH	04/02/2022	Urgent	04/03/2022	4	OL6	Oldham	1	None		f/u April 22	
	03/02/2022	Routine	11/03/2022	5	M30	Manchester	2	Vori		f/u April 22	
	28/01/2022	Routine	18/03/2022	7	B98	Worcestershire	1	Itra		f/u May 22	
	19/02/2022	Routine	25/03/2022	5	SA62	Wales	2	None		f/u April 22	
	27/10/2021	Routine	05/11/2021	2	M18	Manchester	2	Vori		f/u May 22	
	15/11/2021	Routine	17/12/2021	4	WA14	Cheshire	1	None		f/u May 22	

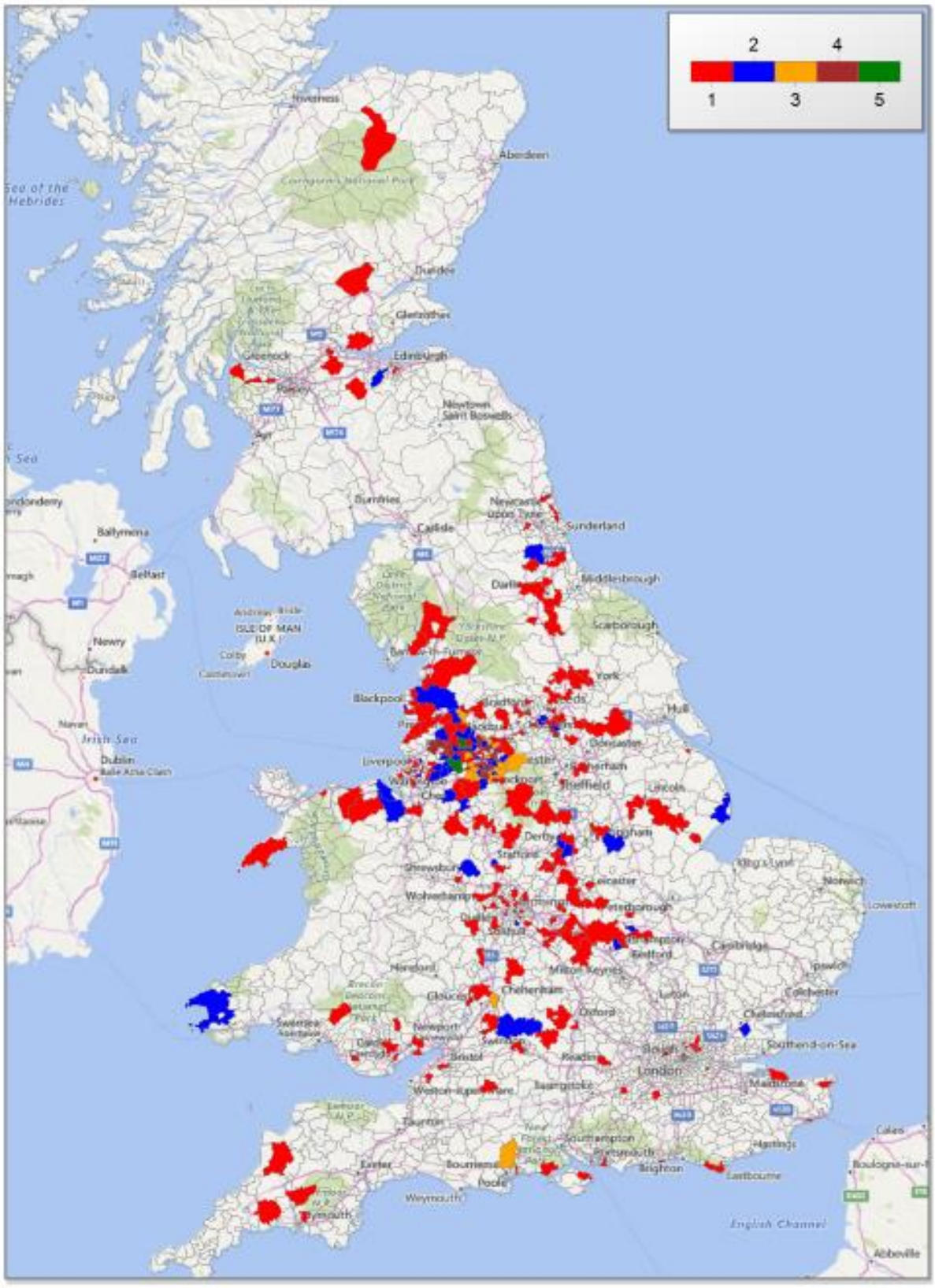
Notes

Transition patients are those that were under NAC service with a non-CPA aspergillus diagnosis that transformed into CPA

Late registration refers to patients who has a complex diagnostic pathway or who were inadvertently not entered into monthly figures at diagnosis.

Appendix 3 Geographical location of patients attending NAC

Graph 1 All patients on NAC service March 2022



Graph 2 New patient referrals 2021-2022

Appendix 4 Discharges from service

Date of discharge	Antifungal at Discharge	Band	Region	Reason
26/03/2021	None	1	Derby	No active CPA
08/04/2021	None	1	Bolton	Stable off therapy
09/04/2021	None	2	Trafford	Stable off therapy
09/04/2021	Itraconazole	1	Wales	Stable off therapy- Patient request
30/04/2021	None	1	Stockport	Stable off therapy
16/04/2021	None	2	Bolton	Stable off therapy
29/04/2021	None	1	Stoke on Trent	No active CPA (ABPA)
08/04/2021	None	2	Plymouth	Stable off therapy
16/04/2021	None	2	Manchester	No active CPA
12/03/2021	None	2	Oldham	No active CPA
30/04/2021	None	1	Chorley	Stable off therapy
23/04/2021	None	1	Middlewich	Stable off therapy
23/04/2021	None	2	Solihull	Stable off therapy
22/04/2021	None	2	Warrington	Semi invasive aspergillosis
06/05/2021	None	2	Scotland	MDT decision
23/04/2021	None	1	Stockport	No active CPA
06/05/2021	None	2	Oldham	No active CPA
07/05/2021	None	2	Middlewich	No active CPA
07/05/2021	None	3	Warrington	No active CPA
05/05/2021	None	2	Manchester	Stable off therapy
06/05/2021	None	2	Stockport	Stable off therapy, DNA x3
20/04/2021	None	2	Blackpool	No active CPA
14/05/2021	None	1	Warrington	Stable off therapy
21/05/2021	None	1	Bolton	Stable off therapy
21/05/2021	None	2	Wigan	No active CPA
03/06/2021	None	2	Wigan	MDT decision, stable off therapy
10/06/2021	None	2	Cheshire	MDT decision, no active CPA (ABPA)
04/06/2021	None	2	Cheshire	No active CPA (ABPA)
29/07/2021	None	2	Glossop	Stable off therapy, active NTM disease
30/07/2021	None	2	West Midlands	No active CPA
29/07/2021	Posa	3	Scotland	follow up locally, patient unable to travel
16/07/2021	None	2	Lancaster	No active CPA
29/07/2021	None	1	Manchester	No active CPA, recent lung cancer diagnosis
18/06/2021	None	2	Halifax	Stable off therapy
22/07/2021	None	2	Wigan	No active CPA (ABPA)
09/07/2021	None	1	Leeds	Stable off therapy
12/08/2021	None	2	Birmingham	MDT decision, No active CPA
23/07/2021	None	2	Rochdale	Stable off therapy
06/08/2021	None	3	Oldham	No active CPA
12/08/2021	None	2	Manchester	No active CPA
30/07/2021	Itraconazole	2	Darlington	Stable off therapy
09/09/2021	None	2	Blackburn	MDT decision, stable off therapy
16/09/2021	None	2	Wigan	MDT decision, no active CPA
16/09/2021	None	1	Warrington	MDT decision, stable off therapy
10/09/2021	None	2	Manchester	dna x 4
13/08/2021	None	2	Wirral	Stable off therapy
13/08/2021	None	1	Gatley	Stable off therapy
20/08/2021	None	2	Trafford	No active CPA
06/08/2021	None	2	Wales	Stable off therapy
22/10/2021	None	1	Birkenhead	No active CPA
29/10/2021	None	2	North Humberside	Stable off therapy
15/10/2021	None	1	Wigan	Stable off therapy
04/11/2021	None	2	Wakefield	No active CPA
04/11/2021	None	2	Manchester	Stable off antifungals
19/11/2021	Itraconazole	1	Stockport	No active CPA
01/10/2021	None	1	Stockport	Stable off antifungals
15/10/2021	None	2	Stockport	Return to Pakistan
15/10/2021	None	1	Manchester	Stable off antifungals
17/11/2021	None	2	Oldham	dna x 3
23/12/2021	None	2	Dukinfield	MDT decision, No active CPA (ABPA)
17/12/2021	None	1	Manchester	Stable off antifungals
09/12/2021	None	1	York	MDT decision, stable off antifungals, prev surgical resection
25/01/2022	None	1	Wigan	Stable off antifungals
13/01/2022	None	2	Manchester	MDT decision, no active CPA
23/12/2021	None	1	Bolton	No active CPA
13/01/2022	None	2	Wales	MDT decision, ABPA, no active CPA (prev lobectomy aspergilloma)
27/01/2022	None	2	Manchester	MDT decision, ABPA, no active CPA
05/11/2021	None	2	Liverpool	No active CPA
14/01/2022	None	2	Manchester	No active CPA
21/01/2022	None	2	Rochdale	Pneumonectomy 2017 for CPA, Stable off antifungals
18/02/2022	None	2	Manchester	No active CPA
25/02/2022	None	1	Dorset	No active CPA post surgery
11/02/2022	None	2	London	No active CPA post surgery
14/01/2022	None	1	Sheffield	Stable off antifungals
25/02/2022	None	2	West Midlands	No active CPA
17/03/2022	None	2	Northwich	Stable off antifungals
25/02/2022	None	2	Stockport	Stable off antifungals
18/03/2022	Voriconazole	2	Scotland	Care transferred to Edinburgh

Appendix 5 Admissions and OPAT activity

MONTH	ADMITTED	DISCHARGED	BED DAYS	PCT	IV TREATMENT/OUTCOME	PROCEDURE	Base Antifungal	
APRIL (1)								
APRIL (2)								
May (1)								
May (2)								
June (1)	21/06/2021	29/06/2021	8	02A		Embolisation		
June (2)	03/06/2021				Micafungin, Success	Lobectomy		Leeds Infirmary
July (1)	30/06/2021	13/07/2021	13	01G		R. upper lobectomy	Itraconazole	
	09/07/2021	14/07/2021	5	27D		Embolisation	Posaconazole	
July (2)	05/07/2021	07/07/2021	2			Embolisation	Posaconazole	Cheltenham Hospital
Aug (1)	03/08/2021	07/08/2021	4	01G		L. lower lobectomy	Isavuconazole	
Aug (2)								
Sept (1)	15/09/2021	23/09/2021	8	01V	Micafungin, Success	L. upper lobectomy		
	11/09/2021	30/09/2021	19	01W		Embolisation	None	
Sept (2)								
Oct (1)								
Oct (2)	14/10/2021		21		Caspofungin, Success			Bradford Royal
Nov (1)	03/11/2021	15/11/2021	12	15E		bi-lobectomy	Posa	
	19/11/2021	27/11/2021	8	42D		R upper lobectomy	Posa	
Nov (2)								
Dec (1)	09/12/2021	10/12/2021	1	00R		Embolisation	None	
Dec (2)								
Jan (1)	15/12/2021	15/01/2022	31	00R	Mica/AmB, Success	L upper lobectomy	Posa	
Jan (2)								
Feb (1)			1	09F	AmBisome, Fail	Embolisation		Southampton General
	14/02/2022	22/02/2022	9	14L	Micafungin, complete via OPAT	Embolisation		
Feb (2)								
March (1)	01/03/2022	03/03/2022	2	0SV		Embolisation	Vori	
March (2)	23/02/2022	03/03/2022	8	14L	Completion of Mica, Success	OPAT		

	Embolisation
	Surgery
	OPAT
	External activity

Appendix 6 Antifungal Trial Data

Posaconazole Drug Trials 2021-22				
Trial start date	**4 month review**	**6 month review**	**Trial outcome**	**Commments**
09/10/2020	Feb-21	Apr-21	Success	Progression on itra, ADR with vori. Patient died April 2022.
28/11/2020	Mar-21	May-21	Success	ADR with itra, prev skin cancer so vori contraindicated.
08/12/2020	Apr-21	Jun-21	Success	ADR wih Vori and itra. Prev good response to Posa then relapsed within 6 months off therapy. Fully sensitive isolate Nov 2020. Negative April 2021.
26/02/2021	Jun-21	Aug-21	Fail	Progression on itra, abn LFT on Vori. 4/8/21 sputum sample showed A. fumigatus resistant to posa. Switch to Isavu Aug 2021
31/03/2021	Mar-21	Sep-21	Success	Prior Itra/Vori/Isav - intolerant. CT not repeated as multiple prior scans and CXR clearly improved.
01/04/2021	Aug-21	Oct-21	Success	Intolerant Itra, Vori and Isav. No repeat CT at 6 months as CXR stable, had >8 CT sans in last 6 years
15/04/2021	Aug-21	Oct-21	ADR	Prior itra and Vori - side effects. Posa stopped May 21 due to peripheral oedema. Switch to Isav.
14/05/2021	Nov-21	Jan-22	Success	Itra - hepatotoxicity. Surgical resection 19/11/21 - confirmed aspergilloma. Posa maintained stability to surgery.
12/07/2021	Nov-21	Jan-22	Success	Stopped Vori due to photosensitivity, brief stop of posa due to high levels in July 2021
01/08/2021	Dec-21	Feb-22	Died	Died 21/09/21 secondary to lung cancer and HAP. No prior antifungal. Started posa after MDT with caveat lung cancer will determine prognosis.
19/08/2021	Dec-21	Feb-22	Success	Dearranged LFTs with Vori
06/09/2021	Jan-22	Mar-22	Success	Failed itra, side effects with Vori.
11/11/2021	Mar-22	May-22	ADR	Prolongation of QT on ECG with Vori. Worsening ECG changes on posa - changed to Isavuconazole.
01/10/2021	Feb-22	Apr-22	Pending	
31/12/2021	Apr-22	Jun-22	Pending	
06/01/2022	May-22	Jul-22	Pending	
10/01/2022	May-22	Jul-22	Pending	
14/01/2022	May-22	Jul-22	Pending	
04/02/2022	Jun-22	Aug-22	Pending	
04/02/2022	Jun-22	Aug-22	Pending	
19/02/2022	Jun-22	Aug-22	Pending	
03/03/2022	Jul-22	Sep-22	Pending	
03/03/2022	Jul-22	Sep-22	Pending	
04/03/2022	Jul-22	Sep-22	Pending	
11/03/2022	Jul-22	Sep-22	Pending	
Success				
Adverse drug reaction (ADR)				
Fail				
Pend to 22/23 data				
Deceased				

Isavuconazole Drug Trials 2021-22

Trial start date	4 month review	6 month review	Trial outcome	Commments
26/11/2020	Mar-21	May-21	Success	Vori - photosensitivity. Posa - neuropathy. Patient chose to stop Isav after 7 months.
01/11/2020	Mar-21	May-21	Died	Patient died 2/6/21 secondary to pneumonia. Non-compliant with therapy so not able to judge response.
03/02/2021	May-21	Jul-21	Success	Detailed MDT discussion. IgG improved, no haemoptysis and QoL improved but radiology not improved. To continue and monitor for resistance
28/05/2021	Sep-21	Nov-21	ADR	Stopped after 2 weeks due to hyponatraemia - after investigation not due to Isav, restarted Nov 2021 (pend)
23/06/2021	Jun-21	Aug-21	Died	Died 08/08/2021, lung cancer
16/08/2021	Mar-21	Sep-21	ADR	ADR - dearranged LFTs
18/08/2021	Aug-21	Oct-21	Fail	ADR to itra and vori. Failed Posa. Declined surgery. Evidence of Isav resistance after 6 months - stopped and moved to iv therapy
25/10/2021	Feb-22	Apr-22	Pending	
05/10/2021	Feb-22	Apr-22	Pending	
12/11/2021	Mar-22	May-22	Pending	
21/01/2022	May-22	Jul-22	Pending	
21/01/2022	May-22	Jul-22	Pending	
15/02/2022	Jun-22	Aug-22	Pending	
18/02/2022	Jun-22	Aug-22	Pending	

Success
Adverse drug reaction (ADR)
Fail
Pend to 22/23 data
Deceased

Voriconazole Drug Trials 2021-22

Trial start date	4 month review	6 month review	Trial outcome	Commments
24/06/2020	Oct-20	Dec-20	Success	ADR with itra. Difficulty with IgG due to covid postal delays so sample processed June 2021
01/11/2020	Mar-21	May-21	Success	Bowel cancer led to weight loss (radiotherapy)
13/11/2020	Mar-21	May-21	Success	Stopped therapy Dec 2021 due to stability
27/11/2020	Mar-21	May-21	Success	Itra resistance
08/01/2021	May-21	Jul-21	Success	Delays in Asp IgG due to postal delivery in Covid - 2 rejected samples. March 2022 47
15/01/2021	May-21	Jul-21	Success	Stopped Aug 2021 due to PN, swapped to posa
01/03/2021	Jul-21	Sep-21	Success	Lobectomy June 2021, stayed on therapy for 1 year post op due to empyema/large residual pleural cavity
02/04/2021	Aug-21	Oct-21	Success	Stoppped April 2022 due to PN - switch to posa
14/03/2021	Jul-21	Sep-21	Success	None
09/04/2021	Aug-21	Oct-21	ADR	Discontinued by patient after 6 weeks. Alcoholism and MH history. Patient requested discharge from service Feb 2022.
13/04/2021	Aug-21	Oct-21	Success	Patient became non-compliant with monitoring so stop/start therapy from Oct 2021
23/04/2021	Aug-21	Oct-21	Success	Progression on itra due to itra/posa resistance. Stopped 01/04/21 due to ADR but re-started 23/04/21
21/05/2021	Sep-21	Nov-21	ADR	Stopped due to hopsital admission with critically severe heart failure
01/06/2021	Oct-21	Dec-21	Died	Patient died 17/11/21, severe fibrosis due to sarcoid
04/06/2021	Oct-21	Dec-21	Died	Patient died 19/7/21, severe emphysema
18/06/2021	Oct-21	Dec-21	Success	CT report minimal reduction in size of aspergilloma, IgG improving. MDT 26/05
18/06/2021	Oct-21	Dec-21	Died	Patient died 14/10/21
15/07/2021	Nov-21	Jan-22	Success	ADR with itra
23/07/2021	Nov-21	Jan-22	Success	Itra CI due to heart failure. Changed after 6 months to Posa due to ADR (PN)
05/10/2021	Feb-22	Apr-22	ADR	Prolonged QT and sub-therapeutic levels. Changed to Posa but QT prolonged further so changed isav
01/11/2021	Mar-22	May-22	ADR	Switched to posa 16/03/22 due to skin cancer risk and photosensitivity
01/01/2022	May-22	Jul-22	Died	Presented as an in-patient critically unwell. 2 weeks vori but stopped due to side effects.
30/09/2021	Jan-22	Mar-22	Pending	
24/12/2021	Apr-22	Jun-22	Pending	
11/03/2022	Jul-22	Sep-22	Pending	

Success
Adverse drug reaction (ADR)
Fail
Pend to 22/23 data
Deceased

Clinical data for Drug Trials 2021-2022

Drug Trial	Date trial started	Weight			MRC			SGRQ			IgG			Radiology		Outcome
Posaconazole		Baseline	4 months	6 months	Baseline	4 months	6 months	Baseline	4 months	6 months	Baseline	4 months	6 months	Baseline	6 months	
Posaconazole	01/04/2021	61	57.2	57.6	NR	4	5	ND	83.67	78.18	159	140	143	Left aspergilloma, severe emphysema, PMF (silicosis)	CXR stable	Success
Posaconazole	12/07/2021	53	50.6	52	2	1	1	33.27	21.03	24.56	491	>200	467	Large RLL aspergilloma, massive haemoptysis in ITU	Sig improvement in cavity size and wall thickness	Success
Posaconazole	19/08/2021	49.25			3			87.14			1175			Increase in LUL cavity with intracavitary material since Feb 21, new right lung cancer		Deceased
Posaconazole	31/03/2021	64	62	62	2	1	1	62.12	11.66	10.00	>200	120	96	Bilateral aspergillomas and cystic bronchiectasis	CXR significant improvement	Success
Posaconazole	19/08/2021	54	54		NR	2	2	27.43	21.24	NR	717	NR	626	LUL cavity with aspergilloma	Decrease in size of mycetoma	Success
Posaconazole	14/05/2021	80.25	in-pt	NR	2	NR	NR	29.75	NR	NR	15	NR	8	RUL cavity with intracavitary material	Stable disease	Success
Posaconazole	26/03/2021	66.6			4			85.38			1093			RUL cavity with intracavitary material		ADR
Posaconazole	09/10/2020	75.8	NR	NR	3	NR	3	45.9	NR	NR	56	45	40	LUL cavity	Stable disease	Success
Posaconazole	08/12/2020	59	66.6	63.5	5	5	4	81.5	81.71	77.01	1408	NR	740	Thick walled cavity LUL with lower lobe consolidation	Thinner wall with less internal material, consolidation resolved	Success
Posaconazole	28/11/2020	63.2	55.7	57.9	2	2	2	25.23	41.27	36.63	145	NR	113	Fibrocytic destruction of LUL with aspergilloma	Sig improvement in intracavitary material	Success
Posaconazole	26/02/2021	53.2	52.8	52	4	4	4	NR	76.34	76.81	947	1018	1002	LUL thick-walled cavitation with aspergilloma	Increase in intracavitary material	Failed
Posaconazole	06/09/2021	66.67	NR	67.9	4	NR	4	85.02	NR	66.07	185	NR	124	RUL fibrocavitary disease, emphysema and ILD	Stable disease	Success
Posaconazole	11/11/2021	73.6						81.72			587			LUL cavitary disease with aspergilloma (prev radiotherapy)		ADR

Drug Trial	Date trial started	Weight			MRC			SGRQ			IgG			Radiology		Outcome
Isavuconazole		Baseline	4 months	6 months	Baseline	4 months	6 months	Baseline	4 months	6 months	Baseline	4 months	6 months	Baseline	6 months	
Isavuconazole	28/05/2021	66.7			4			85.38			1093			RUL cavity with intracavitary material		ADR
Isavuconazole	26/11/2020	57.15	62	NR	2	2	NR	59.14	54.25	NR	118	NR	97	Bilat upper lobe fibrocavitary disease (sarcoid), RUL cavity increasing in size	Stable, no change	Success
Isavuconazole	03/02/2021	46.72	45.2	43.1	5	5	NR	88.27	77.21	NR	1095	NR	771	Massive left aspergilloma, additional NTM disease	Increase in aspergilloma size	Success
Isavuconazole	01/11/2020	NR	50.8	NR	NR	5	NR	NR	88.42	NR	NR	NR	133	Left lung cavitation with mycetomas		Deceased
Isavuconazole	23/06/2021	83			5			69.53			NR			Cavitating lesion RUL		Deceased
Isavuconazole	18/08/2021	52	50.6	49.9	4	4	3	76.81	NR	NR	1002	778	845	Thick walled cavity in LUL with enlarging aspergilloma	Increase in size of aspergilloma	Failed
Isavuconazole	16/08/2021	54.4			2			38.05			460			New thick walled RUL cavity on background ABPA		ADR

Drug Trial	Date trial started	Weight			MRC			SGRQ			IgG			Radiology		Outcome
Voriconazole		Baseline	4 months	6 months	Baseline	4 months	6 months	Baseline	4 months	6 months	Baseline	4 months	6 months	Baseline	6 months	
Voriconazole	14/03/2021	52.15	54	52.9	4	4	NR	91.19	75.4	NR	1824	1221	933	Bilateral thick walled cavities and large RUL aspergilloma, severe emphysema	Reduction in cavity size	Success
Voriconazole	13/04/2021	60.4	NR	57.15	NR	NR	NR	NR	NR	NR	68	34	27	Bullous emphysema, LUL cavity with aspergilloma	Sig reduction in cavity wall thickness and size of aspergilloma	Success
Voriconazole	18/06/2021	79.5	79.5	73.02	NR	4	5	NR	71.59	75.9	869	NR	597	RUL cavitary disease with large aspergilloma, emphysema	Reduction in size of aspergilloma	Success
Voriconazole	23/07/2021	67	60	57.17	4	NR	5	86.18	NR	92.51	585	NR	159	Ank Spond/prev TB apical fibrosis, LUL aspergilloma	Reduction in size of aspergilloma	Success
Voriconazole	21/05/2021	34.95	36.4	38.8	5	5		80.02			52		N/A	Left upper lobe cavity with aspergilloma, bronchiectasis (prev MAC)	Slight reduction in size of cavity	ADR
Voriconazole	02/04/2021	35.45	40	41.7	5	4	NR	NR	80.1	73.14	1066	637	605	RUL cavitation, emphysema	Improvement in surroundiing cavitary conslidation	Success
Voriconazole	01/01/2022	39.9			5			NR			>160			Bilateral apical cavites with mycetoma		Deceased
Voriconazole	01/06/2021	68.70	NR		5	NR		93.55	NR		149	90		Severe fibrosis due to sarcoid, RUL aspergloma		Deceased
Voriconazole	18/06/2021	38.90			4			74.88			725			Bilateral upper lobe cavitary disease, large LUL aspergilloma		Deceased
Voriconazole	01/11/2021	103.56			NR			NR			323			Progression of LUL cavitary lesion and new cavitary LLL lesion		ADR
Voriconazole	01/03/2021	47.20	NR	NR	1	NR	1	3	NR	NR	122	NR	33	RUL cavitation with aspergilloma	Lobectomy June 2021	Success
Voriconazole	09/04/2021	40	NR	NR	1	NR	NR	NR	NR	NR	381	NR	NR	RUL cavity with new large aspergilloma	Stable	Stopped
Voriconazole	23/04/2021	41.7	NR	40	NR	NR	NR	NR	NR	NR	167	191	158	Large multiloculated cavity in righ apex with intracavitary aspergilloma	Stable cavities, reduction aspergilloma	Success
Voriconazole	04/06/2021	45.45			5			89.87			187			Emphysema, biapical cavitary disease, LUL aspergilloma		Deceased
Voriconazole	15/07/2021	50.65	51.71	NR	4	3	NR	66.62	39.62	NR	871	153	120	RUL cavitary disease	Improvement in cavity wall thickness	Success
Voriconazole	05/10/2021	73.65			4			81.72			598			LUL cavitary disease with aspergilloma (prev radiotherapy)		ADR
Voriconazole	13/11/2020	54	52.61	52	5	3	2	72.3	79.18	NR	117	156	73	Upper lobe fibrosis/cavities L>R	Stable	Success
Voriconazole	01/11/2020	69	64	60	2	2	2	31.76	NR	NR	75	NR	46	RUL aspergilloma, background sarcoidosis	Definite reduction in aspergilloma size	Success
Voriconazole	27/11/2020	55	59.7	58.5	3	4	4	79.47	NR	72.96	932	783	543	RUL cavitation with aspergilloma	Significant reduction in aspergilloma	Success
Voriconazole	15/01/2021	45.8	44.4	44.7	3	2	1	44.23	35.09	34.83	126	86	60	Right apical cavitating lung disease with intracavitary material	Stable	Success
Voriconazole	24/06/2020	NR	NR	NR	NR	NR	NR	NR	NR	NR	128	NR	59	LUL cavitating consolidation, severe emphysema	stable CT Nov 2020	Success
Voriconazole	08/01/2021	69.4	64.5	NR	5	4	NR	92.09	92.84	NR	108	NR	47	RUL cavitating lesion, no aspergilloma, severe emphysema	improved CT Nov 2021	Success

Appendix 7 Publications

NAC/MRCM Journal publications 2021/2022

Bongomin, F. and Adetona Fayemiwo, S. (2021) 'Epidemiology of fungal diseases in Africa: A review of diagnostic drivers', *Current Medical Mycology*, 7(1), pp. 63–70. Available at: https://doi.org/10.18502/cmm.7.1.6246.

Bongomin, F. and Otu, A. (2021) 'Utility of St. George's respiratory questionnaire in predicting clinical recurrence in chronic pulmonary aspergillosis', *Therapeutic Advances in Infectious Disease*, 8, p. 20499361211034644. Available at: https://doi.org/10.1177/20499361211034643.

Colombo, S.A.P. *et al.* (2022) 'Defective Interferon-Gamma Production Is Common in Chronic Pulmonary Aspergillosis', *The Journal of Infectious Diseases*, 225(10), pp. 1822–1831. Available at: https://doi.org/10.1093/infdis/jiab583.

Hoenigl, M. *et al.* (2021) 'Global guideline for the diagnosis and management of rare mould infections: an initiative of the European Confederation of Medical Mycology in cooperation with the International Society for Human and Animal Mycology and the American Society for Microbiology', *The Lancet. Infectious Diseases*, 21(8), pp. e246–e257. Available at: https://doi.org/10.1016/S1473-3099(20)30784-2.

Kosmidis, C. *et al.* (2021) 'Impact of self-reported environmental mould exposure on COPD outcomes', *Pulmonology* [Preprint]. Available at: https://doi.org/10.1016/j.pulmoe.2021.05.003.

Mills, R. *et al.* (2021) 'Impact of airway Exophiala spp. on children with cystic fibrosis', *Journal of Cystic Fibrosis*, 20(4), pp. 702–707. Available at: https://doi.org/10.1016/j.jcf.2021.03.012.

Ocansey, B.K. *et al.* (2022) 'Histoplasmosis in Africa: Current perspectives, knowledge gaps, and research priorities', *PLoS Neglected Tropical Diseases*, 16(2), p. e0010111. Available at: https://doi.org/10.1371/journal.pntd.0010111.

Oladele, R.O. *et al.* (2021) 'Standardization of Aspergillus IgG diagnostic cutoff in Nigerians', *Therapeutic Advances in Infectious Disease*, 8, p. 20499361211050160. Available at: https://doi.org/10.1177/20499361211050158.

Prattes, J. *et al.* (2022) 'Risk factors and outcome of pulmonary aspergillosis in critically ill coronavirus disease 2019 patients—a multinational observational study by the European Confederation of Medical Mycology', *Clinical Microbiology and Infection*, 28(4), pp. 580–587. Available at: https://doi.org/10.1016/j.cmi.2021.08.014.

van Rhijn, N. *et al.* (2021) 'Meteorological Factors Influence the Presence of Fungi in the Air; A 14-Month Surveillance Study at an Adult Cystic Fibrosis Center', *Frontiers in Cellular and Infection Microbiology*, 11, p. 759944. Available at: https://doi.org/10.3389/fcimb.2021.759944.

Rowley, J. *et al.* (2021) 'Differential Proinflammatory Responses to Aspergillus fumigatus by Airway Epithelial Cells In Vitro Are Protease Dependent', *Journal of Fungi*, 7(6), p. 468. Available at: https://doi.org/10.3390/jof7060468.

Setianingrum, F. *et al.* (2022) 'A prospective longitudinal study of chronic pulmonary aspergillosis in pulmonary tuberculosis in Indonesia (APICAL)', *Thorax*, 77(8), pp. 821–828. Available at: https://doi.org/10.1136/thoraxjnl-2020-216464.

Van Rhijn, N. *et al.* (no date) 'CYP51 Paralogue Structure Is Associated with Intrinsic Azole Resistance in Fungi', *mBio*, 12(5), pp. e01945-21. Available at: https://doi.org/10.1128/mBio.01945-21.

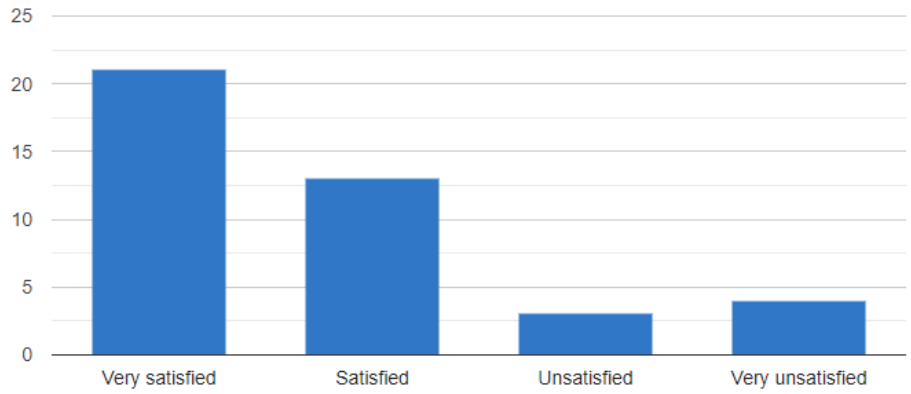
White, P.L. *et al.* (2022) ‘An overview of using fungal DNA for the diagnosis of invasive mycoses’, *Expert Review of Molecular Diagnostics*, 22(2), pp. 169–184. Available at: https://doi.org/10.1080/14737159.2022.2037423.

Appendix 8 Patient Survey Results

Patient's survey 2021-2022

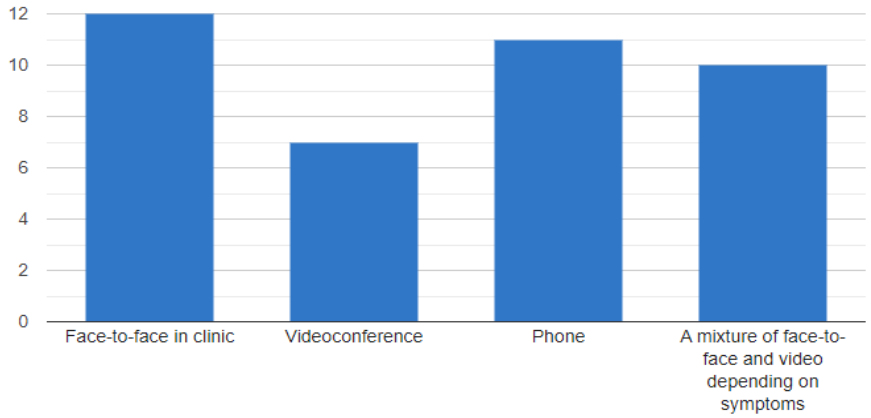
Survey responses

1. If you have had a virtual consultation with our team either by video consultation (Attend Anywhere) or by phone, how well did you feel it went?



7/40 (18%) were unsatisfied or worse with video consultations (2021 5%)
Comments suggest that this is an unpopular option for some for a number of reasons – 5 report it not working, 6 did not know that they had that option.

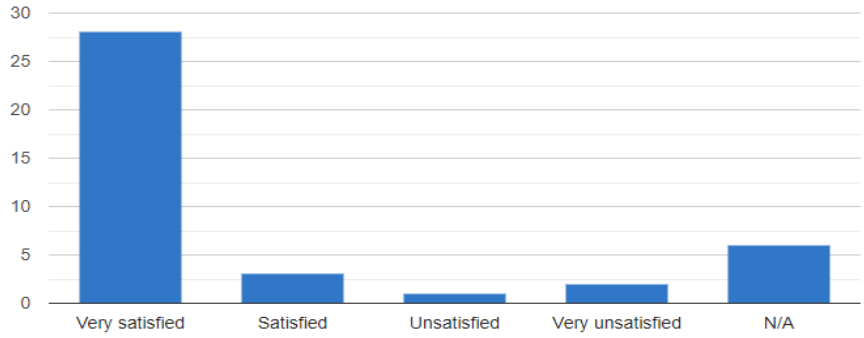
2. If you were given the choice in the future, would you choose to have your consultations face to face at Wythenshawe Hospital, by video consultation or by telephone consultation?



There is clearly no single preferred method of contact amongst this patient population, though videoconference (18%) is the least favourite. In 2020-21 there was a clear preference for face-to-face (52%) and then videoconference (34%) so there have been shifts of preference over the last 12 months away from both videoconference and face-to-face towards phone.

3. How satisfied are you with the courtesy shown to by...

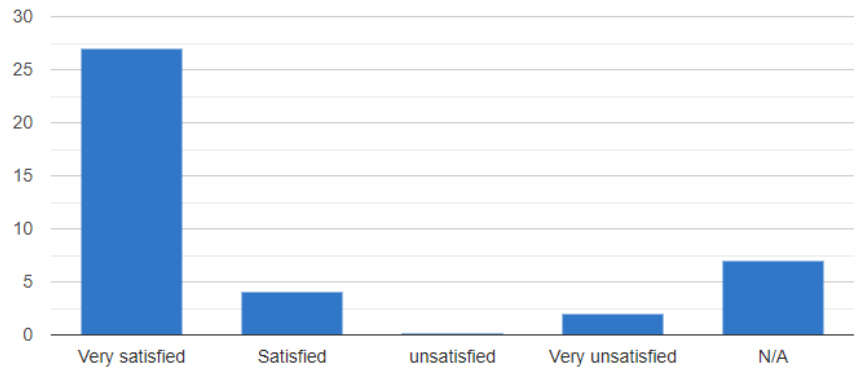
NAC Administrative Team



NAC Administrative Team	Submissions
Very satisfied	28
N/A	6
Satisfied	3
Very unsatisfied	2
Unsatisfied	1

Approval of the NAC Admin team courtesy was high with 31/34 (91%) satisfied or better.

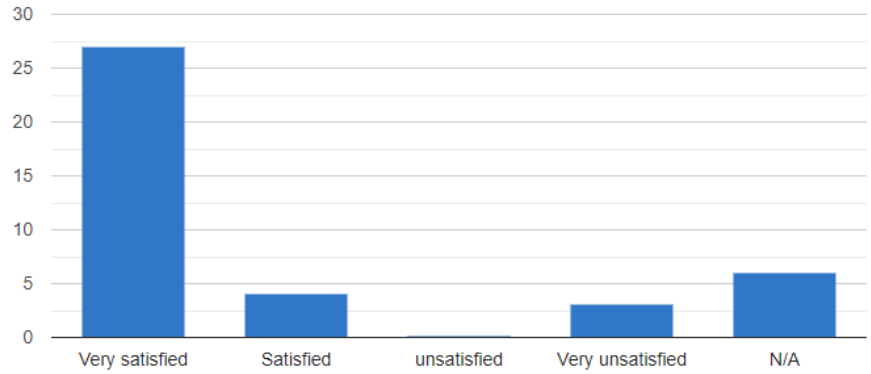
Clinic Nurses



Clinic Nurses	Submissions ▼
Very satisfied	27
N/A	7
Satisfied	4
Very unsatisfied	2
unsatisfied	0

Approval of the Clinic nurses was high with 31/33 (94%) satisfied or better (2021 100%)

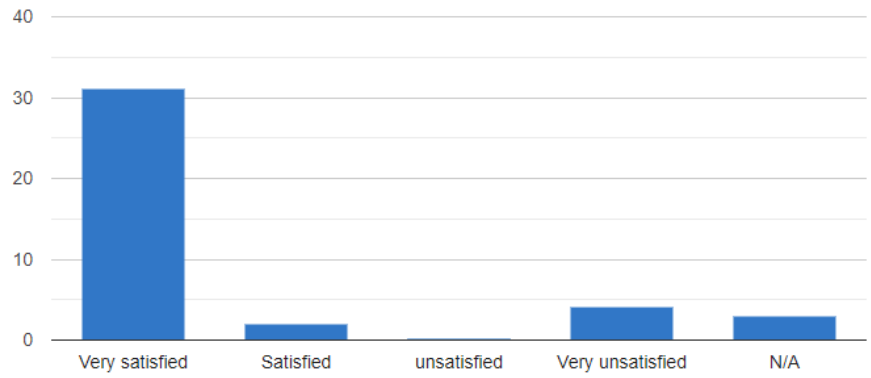
Aspergillosis Specialist Nurses



Aspergillosis Specialist Nurses	Submissions ▼
Very satisfied	27
N/A	6
Satisfied	4
Very unsatisfied	3
unsatisfied	0

Approval of the Specialist nurses was high with 31/34 (91%) satisfied or better (2021 98%)

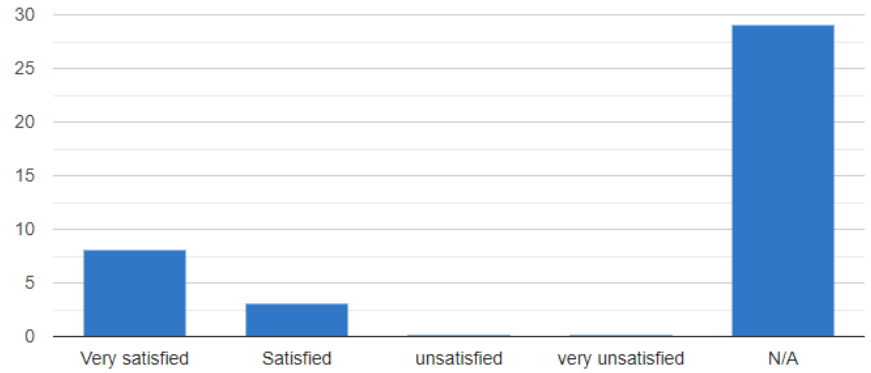
Doctor



Doctor	Submissions ▼
Very satisfied	31
Very unsatisfied	4
N/A	3
Satisfied	2
unsatisfied	0

Approval of Doctor's was high with 33/37 (89%) satisfied or better (2021 92%)

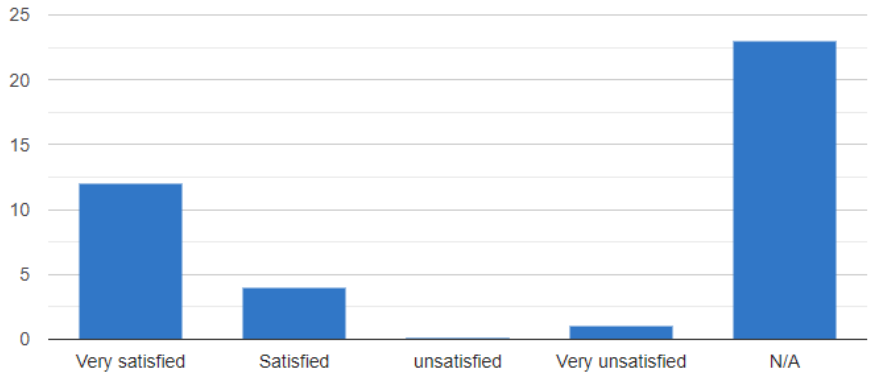
Physio



Physio	Submissions ▼
N/A	29
Very satisfied	8
Satisfied	3
unsatisfied	0
very unsatisfied	0

Approval of Physio's was high with 11/11 (100%) satisfied or better (2021 97%)

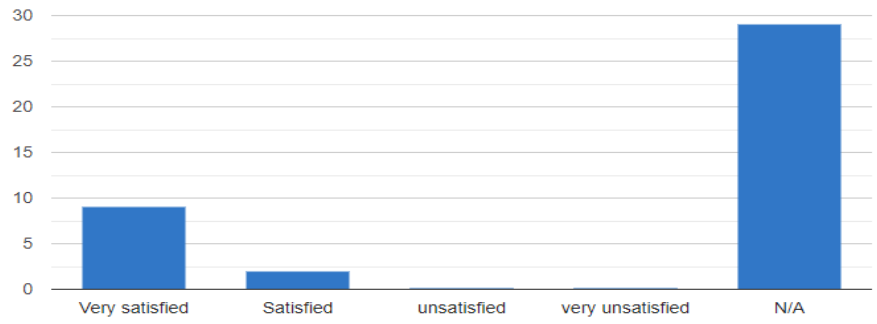
CARES team (Commmunications)



CARES team (Commmunications)	Submissions ▼
N/A	23
Very satisfied	12
Satisfied	4
Very unsatisfied	1
unsatisfied	0

Approval of CARES team was high with 16/17 (94%) satisfied or better (2021 96%)

Specialist Pharmacist

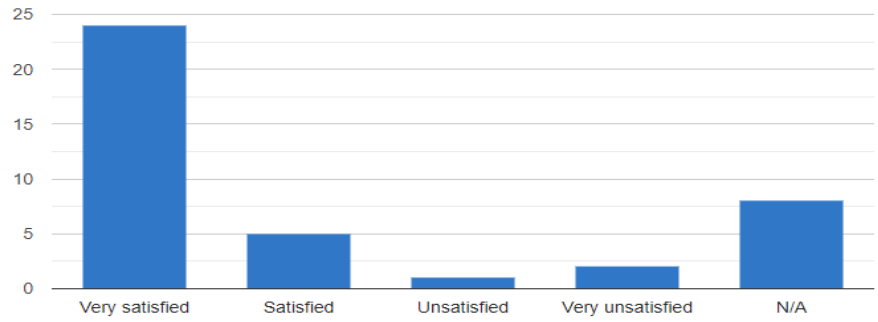


Specialist Pharmacist	Submissions
N/A	29
Very satisfied	9
Satisfied	2
unsatisfied	0
very unsatisfied	0

Approval of Specialist pharmacist was high with 11/11 (100%) satisfied or better.

4. How satisfied were you with the communication and care...

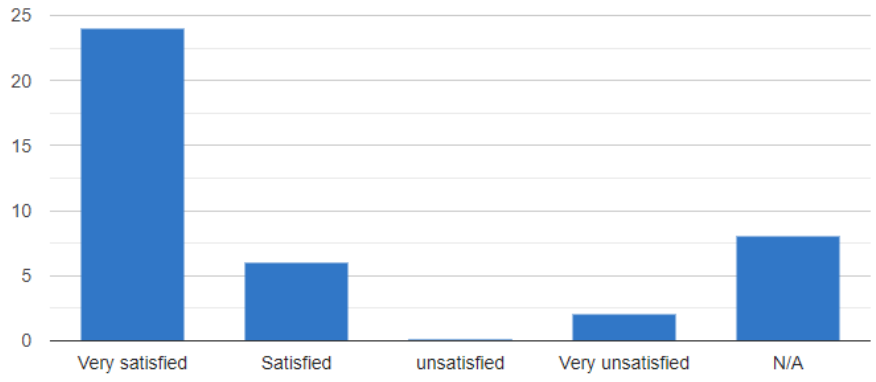
NAC Administrative Team



NAC Administrative Team	Submissions
Very satisfied	24
N/A	8
Satisfied	5
Very unsatisfied	2
Unsatisfied	1

Approval of Admin team was high with 29/32 (91%) satisfied or better.

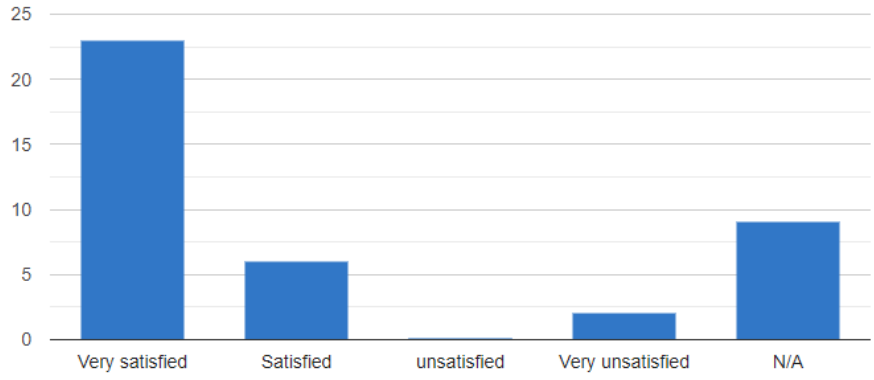
Clinic Nurses



Clinic Nurses	Submissions ▼
Very satisfied	24
N/A	8
Satisfied	6
Very unsatisfied	2
unsatisfied	0

Approval of Clinic nurses was high with 30/32 (94%) satisfied or better.

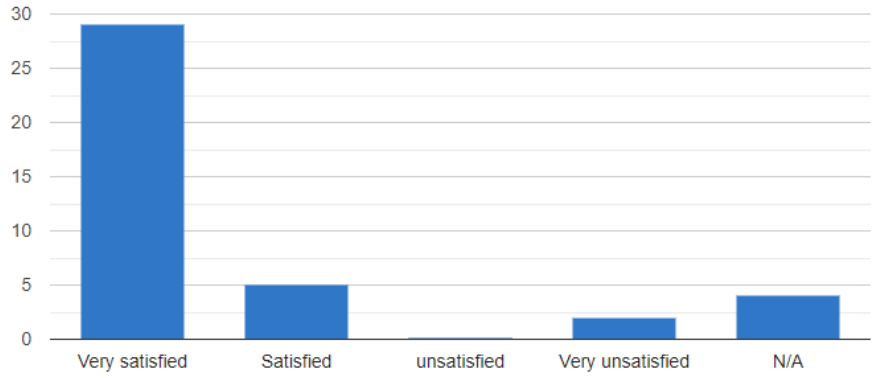
Aspergillosis Specialist Nurses



Aspergillosis Specialist Nurses	Submissions ▼
Very satisfied	23
N/A	9
Satisfied	6
Very unsatisfied	2
unsatisfied	0

Approval of Specialist nurses was high with 29/31 (94%) satisfied or better.

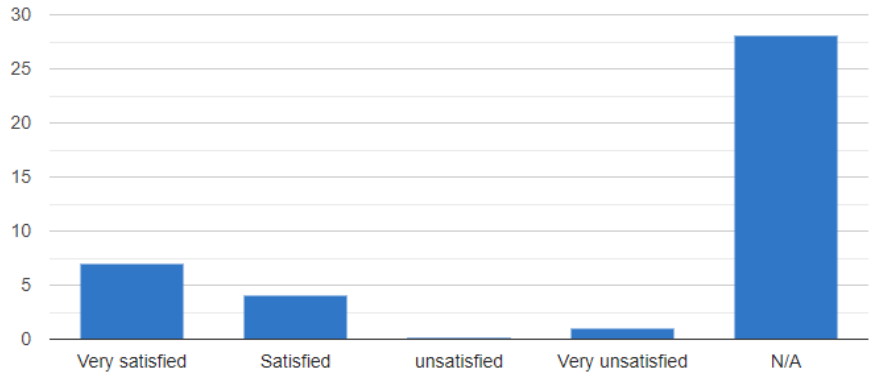
Doctor



Doctor	Submissions ▼
Very satisfied	29
Satisfied	5
N/A	4
Very unsatisfied	2
unsatisfied	0

Approval of Specialist nurses was high with 34/36 (94%) satisfied or better.

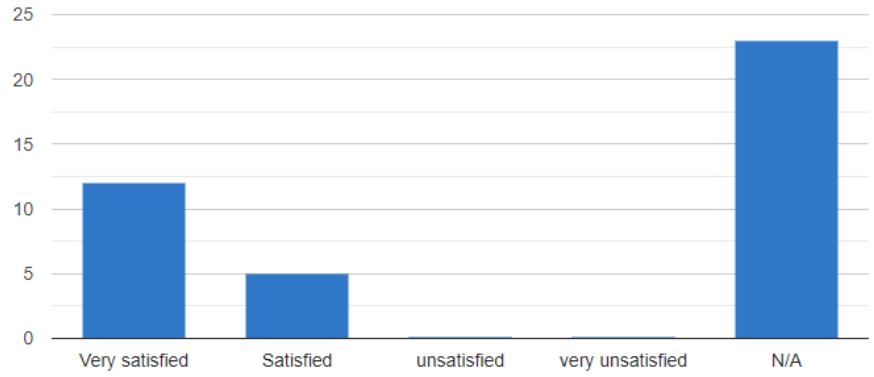
Physio



Physio	Submissions
N/A	28
Very satisfied	7
Satisfied	4
Very unsatisfied	1
unsatisfied	0

Approval of Physio's was high with 11/12 (92%) satisfied or better.

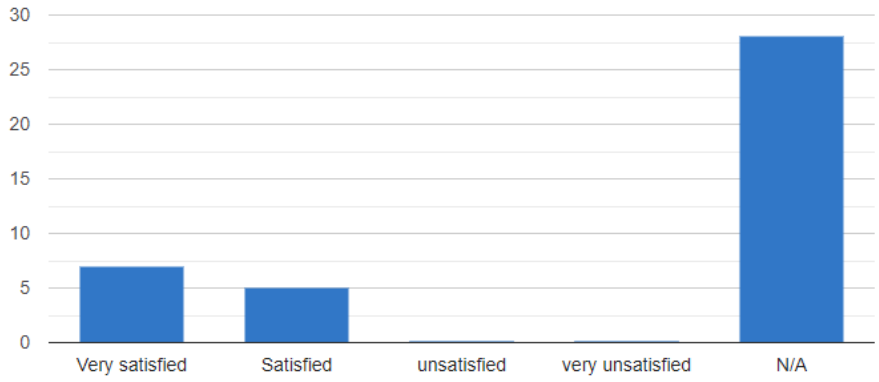
CARES team (Commmunications)



CARES team (Commmunications)	Submissions ▼
N/A	23
Very satisfied	12
Satisfied	5
unsatisfied	0
very unsatisfied	0

Approval of CARES team was high with 17/17 (100%) satisfied or better.

Specialist Pharmacist

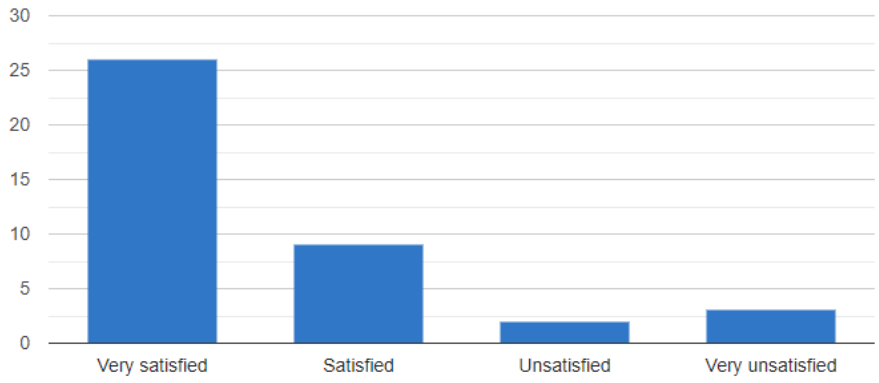


Specialist Pharmacist	Submissions ▼
N/A	28
Very satisfied	7
Satisfied	5
unsatisfied	0
very unsatisfied	0

Approval of Specialist pharmacist was high with 12/12 (100%) satisfied or better.

There were no negative comments that we could use to improve staff courtesy and care (Q3 & 4).

5. How satisfied are you with the communication received regarding your clinic appointments?



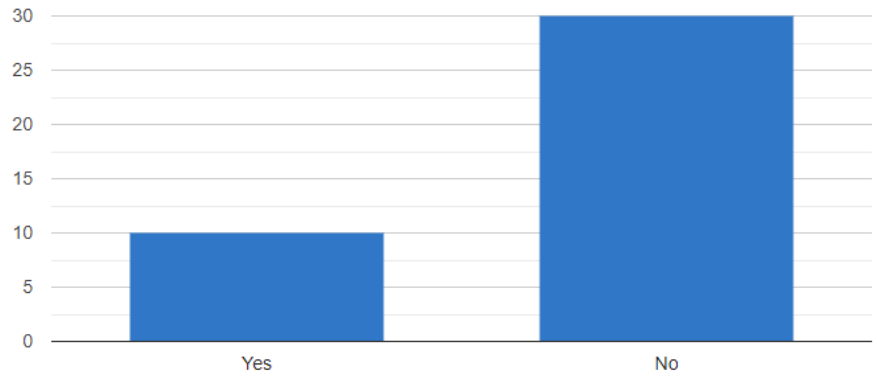
5. How satisfied are you with the communication received regarding your clinic appointments?	Submissions
Very satisfied	26
Satisfied	9
Very unsatisfied	3
Unsatisfied	2

Approval of communication was high with 35/40 (88%) satisfied or better. There are a few hints in the comments (below) about how this rating may still be improved.

Comments about the clinic appointment system

Comments about the clinic appointment system
Good, I was able to ring specialist nurse and get an appointment which was overdue
I was asked to ring for an appointment and then sent one. Both letters arrived on same day which was confusing.I
I'm not getting my appts sent out and am having to chase them
One problem: having changed an appt, the system kept reminding me about the old one.
Plenty of information regarding attendance, Covid precautions etc
Should be more morning appointments offered
Very clearly marked and staff helpful
Very good if appointment for clinic
Was told i was a DNA fif aoot at clinic, when appr was booked ad a telephone consultation on the appt letter
Would like a letter with a resume of what has been discussed as under several chest teams at other hospitals and would help my care

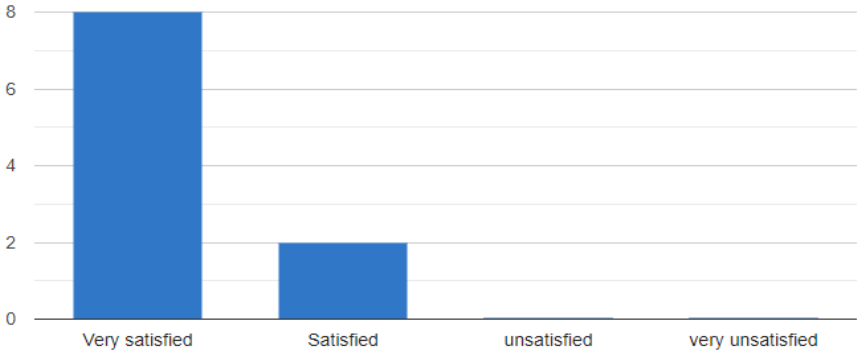
6. Have you had a consultation inbetween clinic appointments with one of our specialist nurses?



6. Have you had a consultation inbetween clinic appointments with one of our specialist nurses?	Submissions
No	30
Yes	10

25% of patients who replied to the survey had had a consultation between clinic appointments.

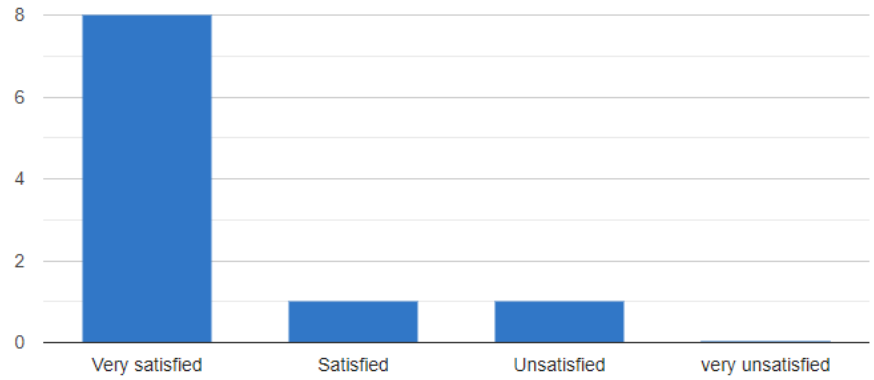
Knowledge of condition



Knowledge of condition	Submissions
Very satisfied	8
Satisfied	2
unsatisfied	0
very unsatisfied	0

100% of responses were satisfied or better with the knowledge of condition apparent from the Specialist nurses (2021 100%).

Communication

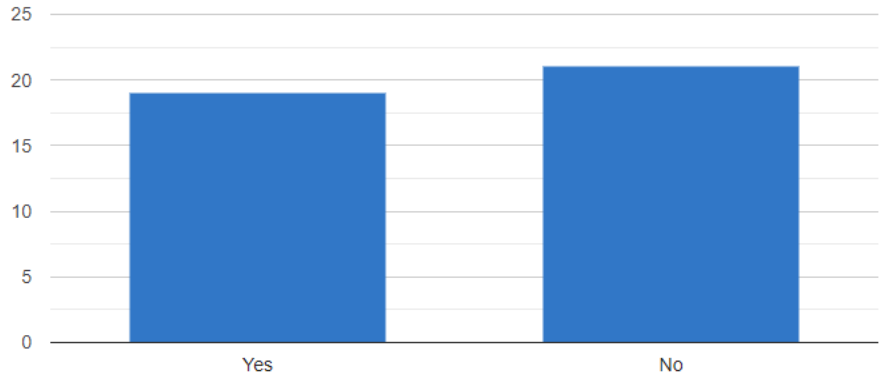


Communication	Submissions ▼
Very satisfied	8
Satisfied	1
Unsatisfied	1
very unsatisfied	0

9/10 (90%) of responses were satisfied or better with Specialist nurses communication (2021 100%).

Any comments?
A couple of times I have had to chase the nurse specialist up for actions to be completed
N/A
The physio has phoned me.
They are v helpful. I've had problems getting bloods done in lockdown, my surgery won't test for aspergillus but the nurse arranged for me to come in and have bloods done in clinic I
Today was first appointment
Very pleased with service

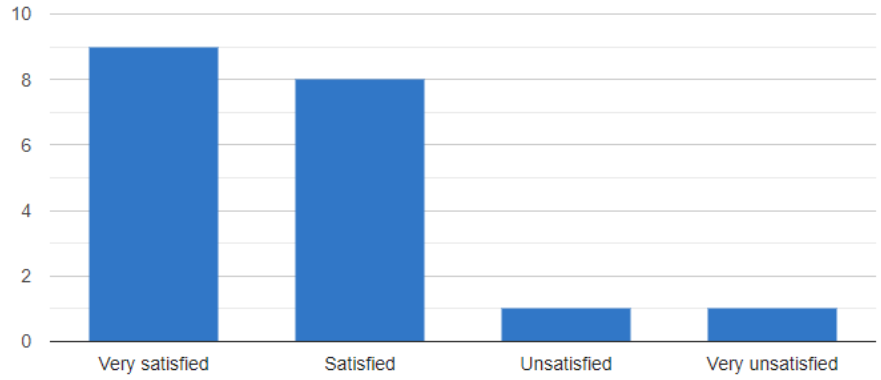
7. Have you received any information leaflets about your condition?



7. Have you received any information leaflets about your condition?	Submissions
No	21
Yes	19

21/40 (53%) of patients who responded had not received any leaflets

a. How satisfied are you with the information you received about your condition?



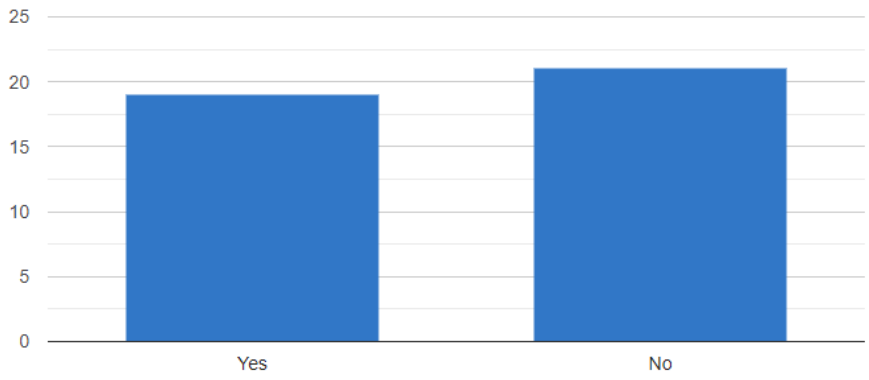
a. How satisfied are you with the information you received about your condition?	Submissions
Very satisfied	9
Satisfied	8
Unsatisfied	1
Very unsatisfied	1

17/19 (90%) were satisfied or better with information received (2021 95%)

Any comments?

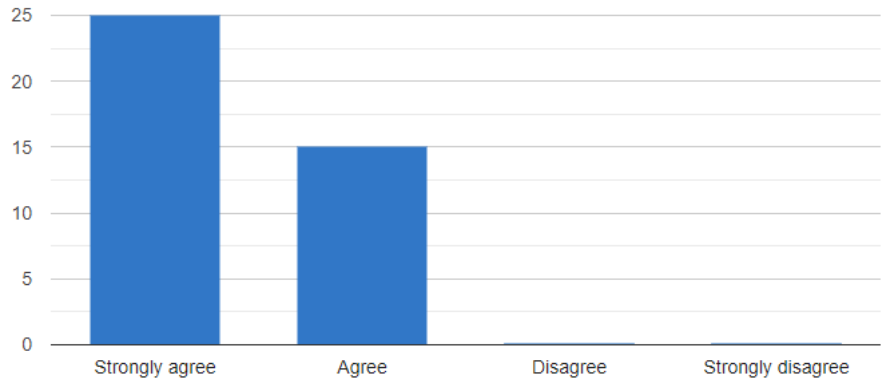
Any comments?
Just at the first stages so have no idea as to what will follow
Would be useful
Would like to to show family / friends to explain as difficult for them to grasp am understanding

8. Did one of our team members tell you about potential symptoms regarding your illness or medication to watch out for at home?



19/40 (48%) of patients had been told about symptoms to be aware of at home (2021 76%) which is quite a large drop**
** Action point A

9. When you had important questions to ask a member of the NAC team did you get answers that you could understand?

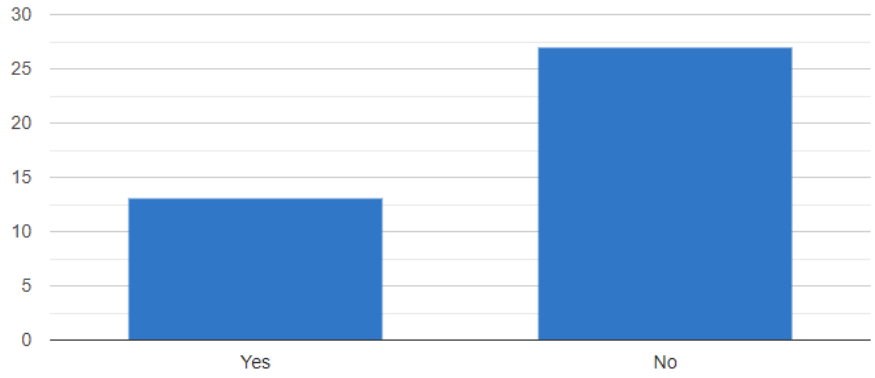


40/40 (100%) agreed that they could understand the answers given by NAC staff when they asked them questions.

Any comments?
Always in clinic not on phone
As I could'nt think of any questions to ask , it doesn.t apply
I've asked specialist nurse to refer two questions I have to the doctor. I hope they will answer them in follow up letter to GP

Patients were asked if they would like to hear more about palliative care support:

10. Is this something you would like to know more about?

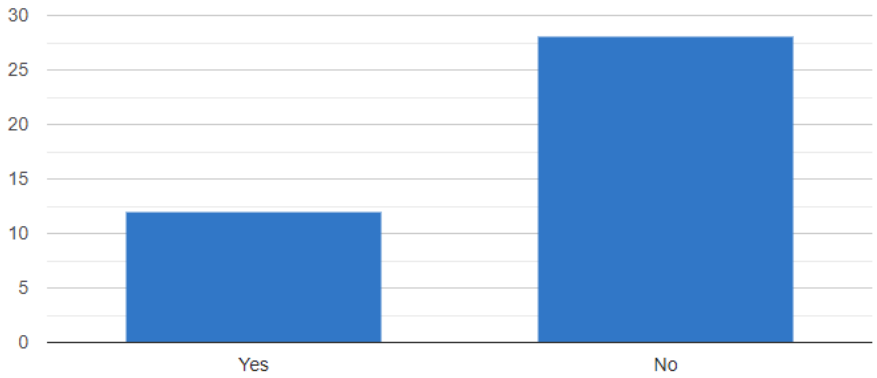


10. Is this something you would like to know more about?	Submissions ▼
No	27
Yes	13

13/40 (33%) stated an interest in hearing more about palliative care (2021 46%) which is a drop on 2021 figures but still a large increase on earlier years (2020 & 2019 10%).**
**Action point B

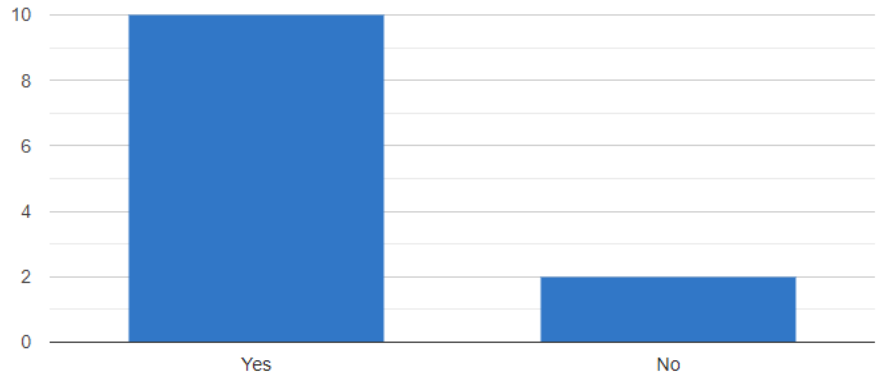
Any comments?
I did'nt ask about what sort of treatment mat be available should it be offered
Not at the moment
Not necessary at present.

11. Have you ever had an in-patient stay here as a NAC patient at Wythenshawe Hospital? This might have been for treatment of Chronic Pulmonary Aspergillosis (CPA) and/or surgery related to NAC treatment.



12/40 (30%) have had an in-patient stay as a NAC patient at Wythenshawe Hospital (2021 34%).

If yes did you feel you were treated with respect and dignity while you were in hospital?



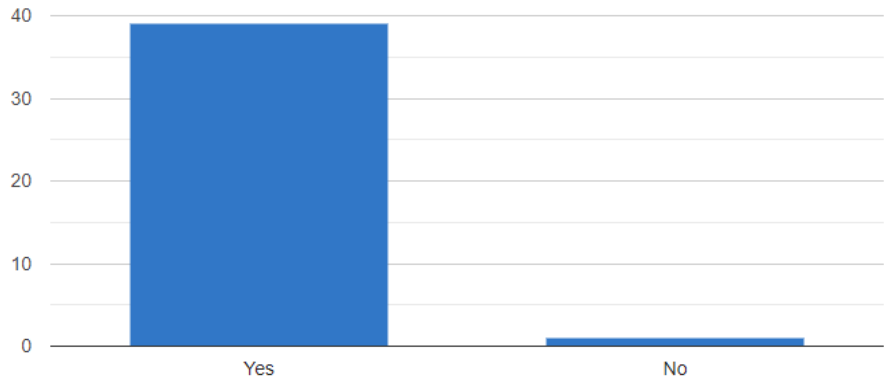
If yes did you feel you were treated with respect and dignity while you were in hospital?	Submissions ▼
Yes	10
No	2

10/12 (83%) felt that they were treated with respect and dignity (2021 95%).

We felt this question requires to be re-phrased next year to capture only in-patient stays within the last year as unsatisfied responses related to treatment years previously. We are aware we have very few in-patient stays now and our wards have changed significantly since the pandemic. We will also add a question to ask if a concern or complaint was raised at the time if they felt unsatisfied with their in-patient care.

Any comments?
I was admitted when newly diagnosed and stayed in for about a week. I had a bronchoscopy, I think I was a Nac in patient.
I've been admitted for low sodium levels but not chest problems
Not since 1967 when Aspergillosis first diagnosed
Staff are great
This was in 2018. I object strongly to the strip search for bruising etc on admission. Also sleep was impossible due to noise. I asked to be transferred to OPAT which worked very well.
Very good
Was not at the most recent appointment. It was in 2019.

12. Would you recommend Wythenshawe Hospital to friends and family?



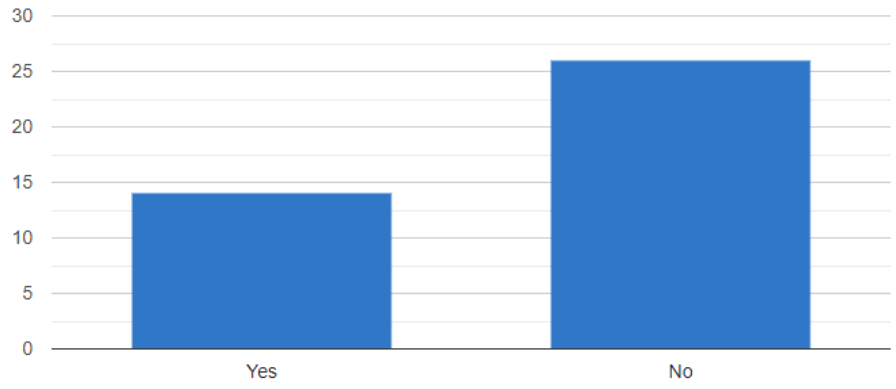
12. Would you recommend Wythenshawe Hospital to friends and family?	Submissions ▼
Yes	39
No	1

39/40 (98%) would recommend Wythenshawe Hospital to friends and family (2021 100%).

If you can, please give us a few details why.
A centre of excellence eg NAC
Always very professional
Caring and thorough
East to access, plenty of parking and lovely staff
Excellent care and attention throughout my time being looked after by the wythenshaw team
Fantastic care given by experienced and knowledgeable people.
Fantastic hospital and staff
Friendly staff and the centre of excellence for the uk
Had been treated at my local hospital then in 2014 was seen at wythenshawe.
I Live in Liverpool don't think they'll come to Manchester
I've been to A and E recently for chest infections and AF, a few times. They are coping admirably under pressure. A and E don't seem to do blood levels of aspergillosis.? They did send off sputum but not sure if it was tested for aspergillus?
If the rest of the hospital staff are as good as the ones I met on my visit, then they would be well looked after
Its a specialist centre with more knowledge than local hospitals
Outpatients. I cannot speak for inpatient stay
Quality of care is excellent, courtesy and kindness too. The clinicians make me feel welcome and are always well informed about my condition.
The national aspergillosis Centre is a great facility
The staff was excellent and make you feel like your The only person that matters
Treated well
Very knowledgeable and helpful
Very professional but the main reason would be very friendly

Comments are universally positive.

13. We provide a postal service for drug levels and sputum samples. If you have used this service have you any comments or ideas on how this can be improved?



14/40 (35%) of patients who replied have used the postal service (2021 49%).

Your comments
N/a
Very good
All the instructions for sending samples through the post were clearly informative
Always worked well
Bloods d samples not always received in correct condition so not very successful
Easier and better packaging for returning the samples
Good service
Great service.
I have the kit and may use it in future for sputum.
I have used the postal service many times without any problems at all.

It suits me well, as I live so far away from Wythenshawe and the 2 to 3 hour drive is getting a bit tedious.
I've not really used this service as I'm not keen on my gp practice
Live 10 mins away so can drop off sputum samples
Not used yet so put yes as I have confidence it will be fine
Works well
Works well, but always some confusion at the surgery regarding which bottles to use
Would like results before witinh months to speak to doctors for peace of mind we

Comments reflect that the service is easy to use and a welcome alternative to travelling to NAC.

14. We have commissioned a company to deliver anti fungal drugs to patient's home. If you have had this service do you have any comments

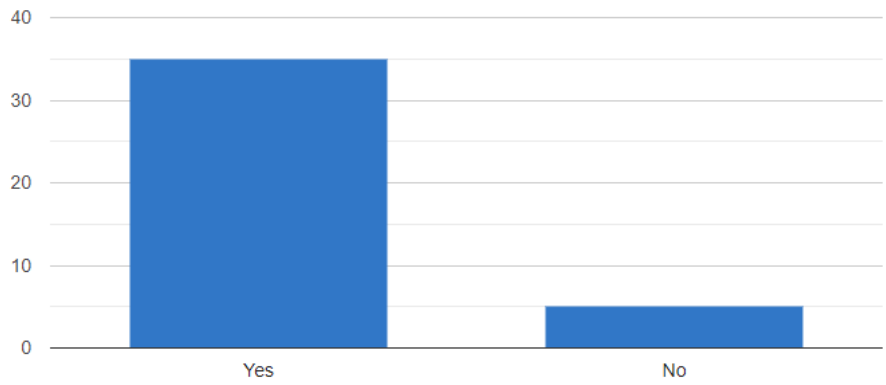
6/40 (15%) of patients have used this service (2021 46%) and have made the following comments:

Your comments
N/a
At the moment not on any drugs from wythenshawe
Did not know this was available
Good service
Great idea and it saved me a special journey to collect my drugs
I have never used this service
N/A
Not had this service
Not taking anti fungal drugs
Not used
On 3 occasions the medication hasn't turned up. Also it's a nightmare to telephone the company
They're very helpful
Was great when I used it

15. Do you travel to clinic by hospital transport?

2/40 (5%) travel to NAC clinic by hospital transport of which 100% were very satisfied (2021 7%).

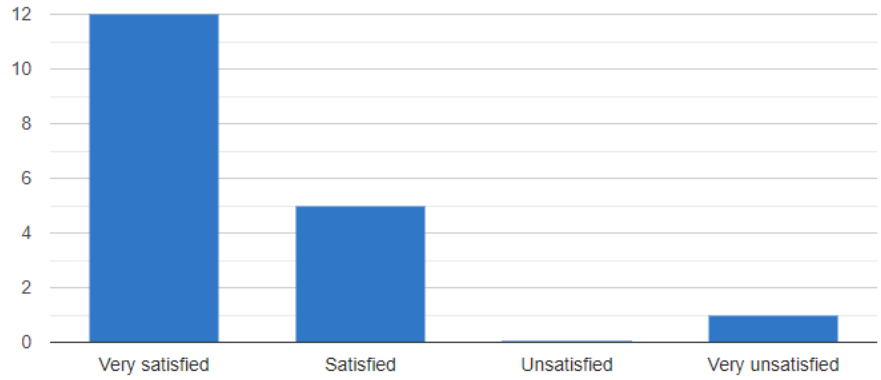
16. Are you generally happy to participate in clinical research?



16. Are you generally happy to participate in clinical research?	Submissions
Yes	35
No	5

35/40 (88%) of patients were happy to participate in clinical research (2021 88%)

a. If you already have, were you happy with the procedures and consent process?

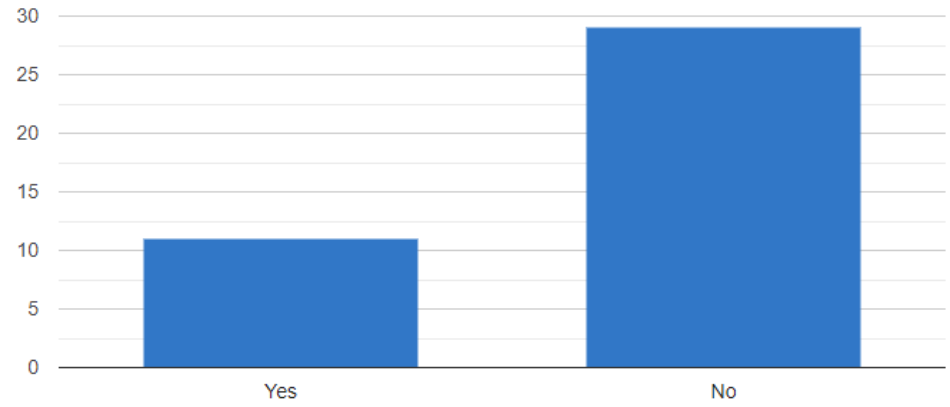


a. If you already have, were you happy with the procedures and consent process?	Submissions
Very satisfied	12
Satisfied	5
Very unsatisfied	1
Unsatisfied	0

17/18 (94%) were happy with procedures and consent process (2021 100%).

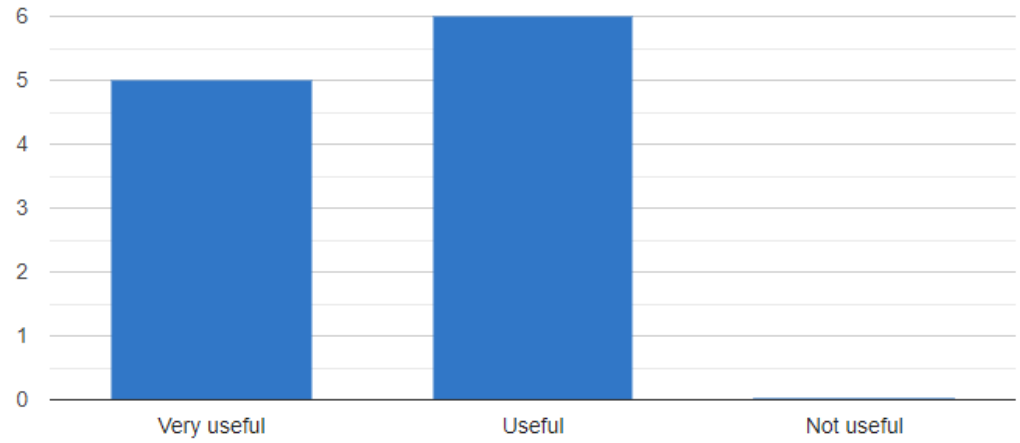
Any comments?
N/a
Distance makes this a challenge however
If it can help people like my self
If the researches are clearly explained and consent abided by then I am quite happy

17. We have developed several patient information leaflets that are available online at https://aspergillosis.org/information-leaflets/ and on request in clinic. Have you seen them?



11/40 (28%) have seen the leaflets.

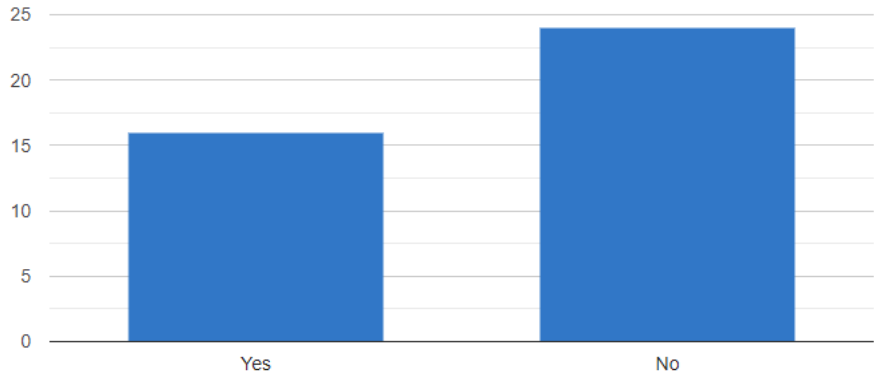
a. If you have seen them, how useful do you think they were for you?



11/11 (100%) thought the leaflets were useful or very useful (2021 93%) which is the third increase in this figure over the last here years. Clearly the leaflets are improving.

b. Is there any other information that you would like to receive information about?
No
Abpa
Anything that is relevant to my condition
If I am to go ahead with whatever I am given then yes please
No I'm ok
The Zoom meetings which I could attend
Unable to print
Would like more information on my illness

18. Have you visited the new Aspergillosis patient's and carers website? (https://aspergillosis.org/)



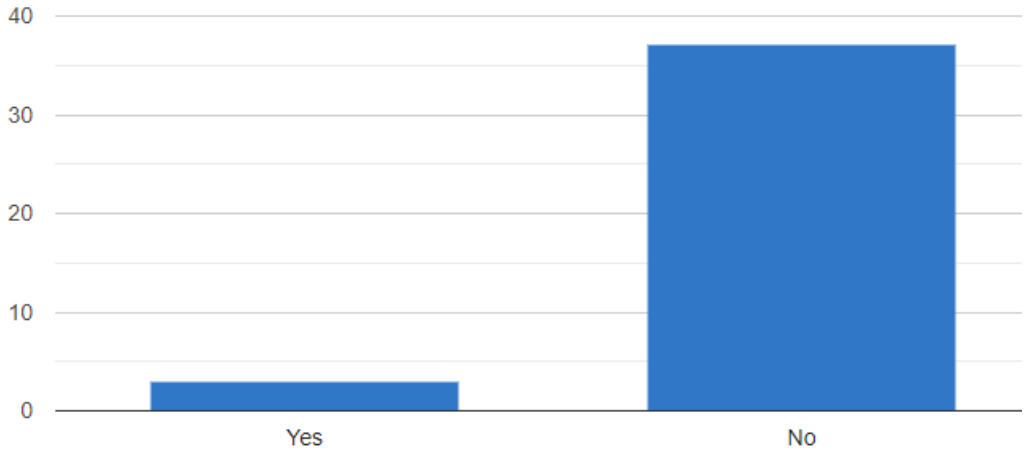
18. Have you visited the new Aspergillosis patient's and carers website? (https://aspergillosis.org/)	Submissions ▼
No	24
Yes	16

16/40 (40%) of patients had visited aspergillosis.org (2021 44%). 100% of those that had visited were satisfied or very satisfied with the website.
When asked if there was a reason why they had not visited the website there were two types of response:

1. People who had never heard of the website (8/14 57%) ** Action point C
2. People who were not interested in reading about aspergillosis (3/14 21%)

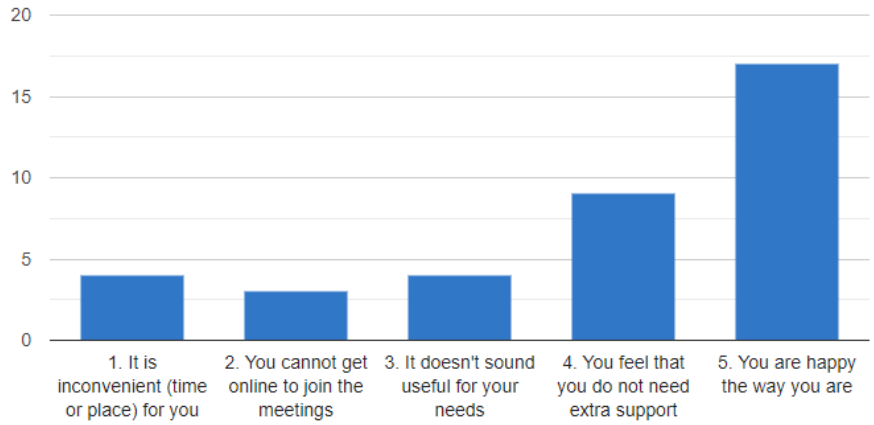
19. We have regular monthly patient meetings here in Manchester at 13:00 on the first Friday of every month, currently presented on Zoom online.

Have you attended this patient's meeting on Zoom or Facebook?



3/40 (7.5%) of patients had attending a meeting which is a drop in numbers from 2021 (21%) when we appeared a lot more via videoconference (i.e. every day) during the first wave of the COVID-19 pandemic. This is still an increase over 2020 & 2019 figures (3% & 0% respectively).
Of those that did attend a meeting and left a comment, both found them informative and very useful.

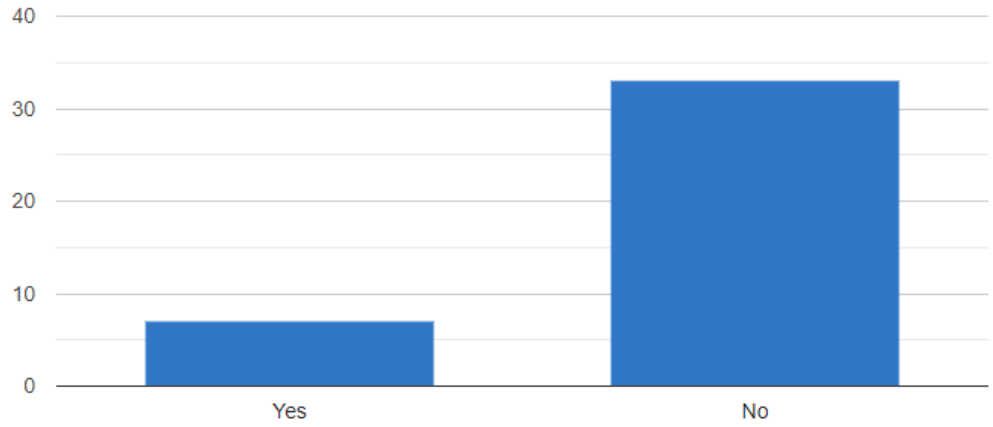
b. If no, please tick the following comments if relevant



b. If no, please tick the following comments if relevant	Submissions ▼
5. You are happy the way you are	17
4. You feel that you do not need extra support	9
1. It is inconvenient (time or place) for you	4
3. It doesn't sound useful for your needs	4
2. You cannot get online to join the meetings	3

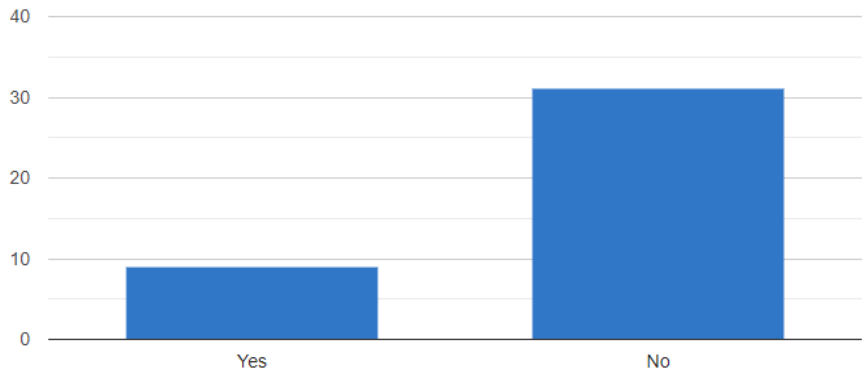
Most people (30/37 81%) did NOT attend a meeting because they had no need to do so (i.e. they were happy with their current level of knowledge and support) rather than lack of access/inconvenient time (7/37 19%). This suggests that 19% might attend if we could improve access (2021 22%).
As time goes by we could assume that these who currently cannot get access will eventually be able to get online as barriers reduce and would be able to watch the recording of the meeting, thus removing the problem of the meeting happening at an inconvenient time.
Comments tell us that 60% did not know about the Zoom meetings. ** Action point D

20. We have a very active Aspergillosis Support group (>2500 members) on Facebook (https://www.facebook.com/groups/aspergillussupport/). Are you a member?



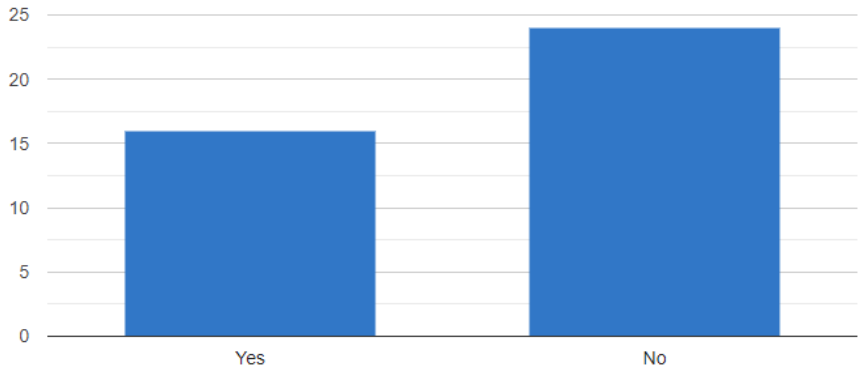
33/40 (82%) of patients who commented are not members of the NAC Facebook support group (2021 57%). ** Action point E

21. There is a twice-weekly online social chat for patients & carers on Thursday at 10.00am and Tuesday at 2pm, currently using Zoom software. You can attend using your phone or any computer. The link is https://us02web.zoom.us/j/405765043 Code: 784131. Have you ever heard of it? If not please contact us at NAC.Cares@mft.nhs.uk or phone 0161 291 5866.



9/40 (23%) of patients who commented have heard of NAC social chat Zoom groups (2021 41%). 3/9 (33%) had attended a meeting (2021 27%) ** Action point F

22. The CARES team here at NAC have set up the Telegram App for your smartphone to enable you to contact the NAC CARES team completely privately and securely. This is useful for you to ask the team about any issues that you make be concerned about relating to NAC, and enables us to send you information too. Would you like to hear more about this?



16/40 (40%) would like to hear more about Telegram. **Action point G

23. Do you have any other general comments about the NAC service?

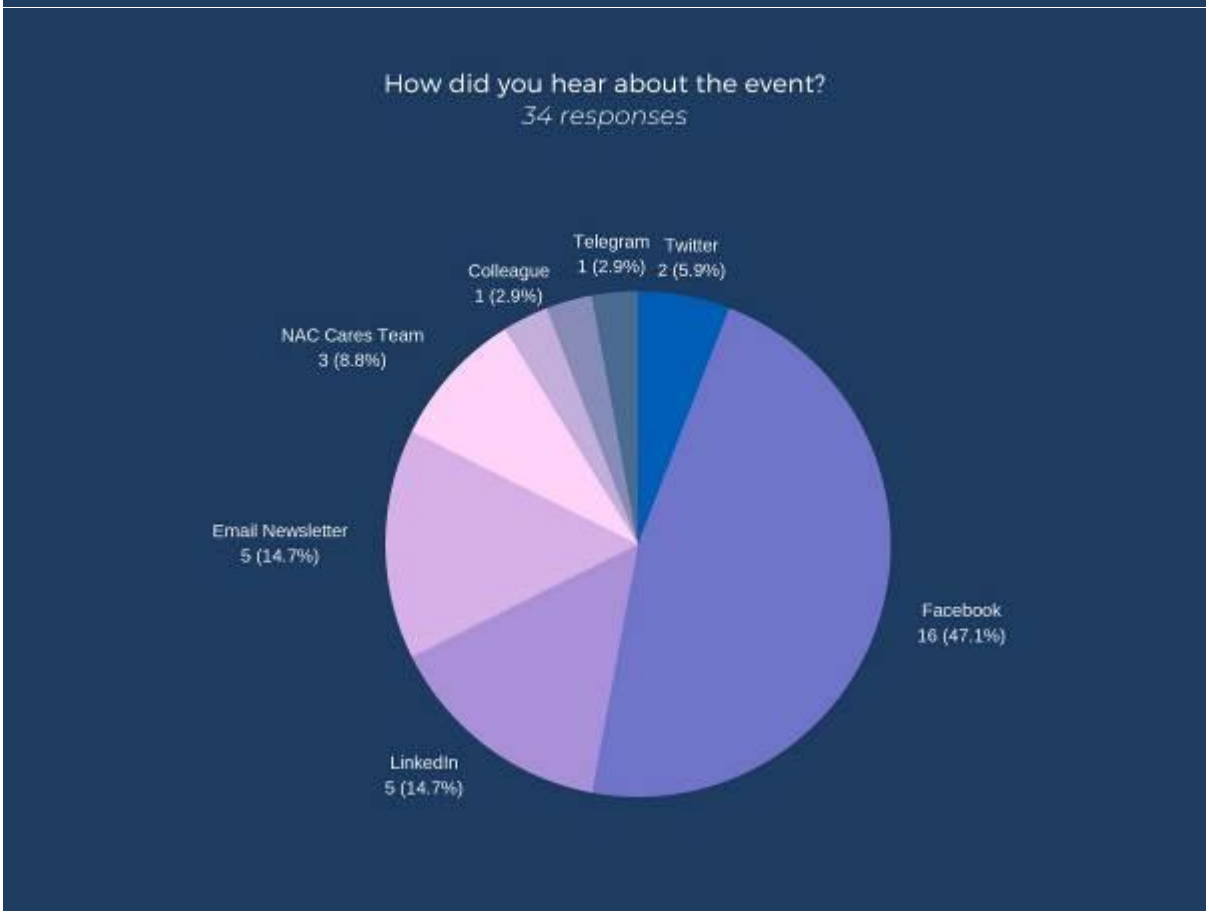
23. Do you have any other general comments about the NAC service?
Could this service help me with my benefits
Everyone is very helpful and friendly and I think that goes along way. God bless you all
Everything's been absolutely fine
First time used today and I feel reassured and confident that the process is well designed and well staffed.
Great hospital and great service.
I have never been to a hospital where they don't treat you like a patient they treat you as a person and they don't rush you they make you feel very welcome
I'm grateful for the improvement in my condition
It has been very helpful with caring staff. Really appreciate it
It is a great service with fantastic people!
My contact has been with specialist nurses who are excellent. Thank you
No
No I'm very grateful to everyone that helps me thank you all
None.
Not at the moment
Nothing to add except every one Ive met are keen to help or look up things for you or send video links.
Probably be discharged soon
Very helpful, very professional and caring

** Patient with comment about benefits to be contacted with suitable information

Appendix 8 World Aspergillosis Day Feedback

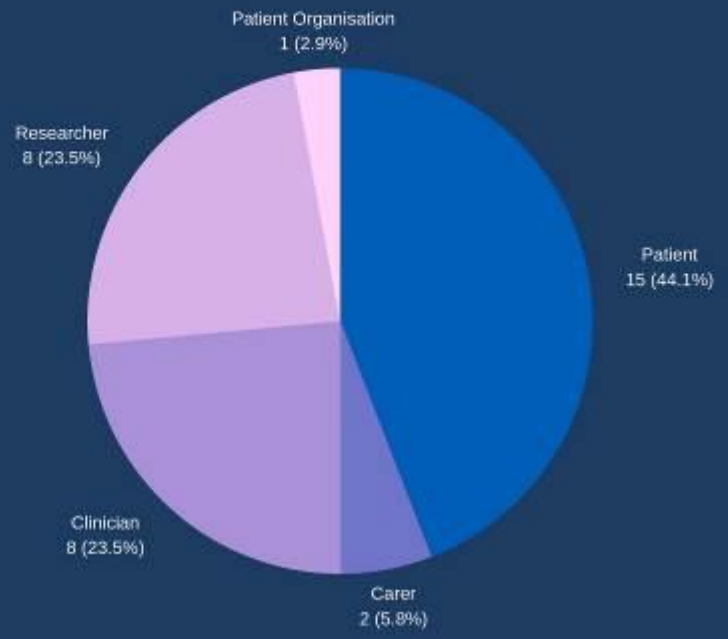
World Aspergillosis Day 2022

Seminar Series - Post Event Survey Results



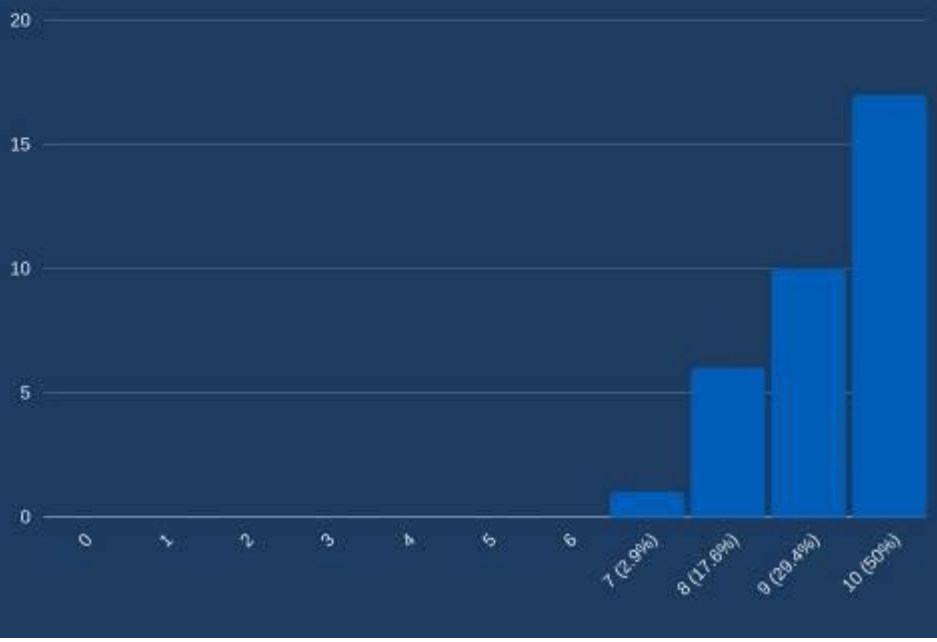
How would you best describe yourself?

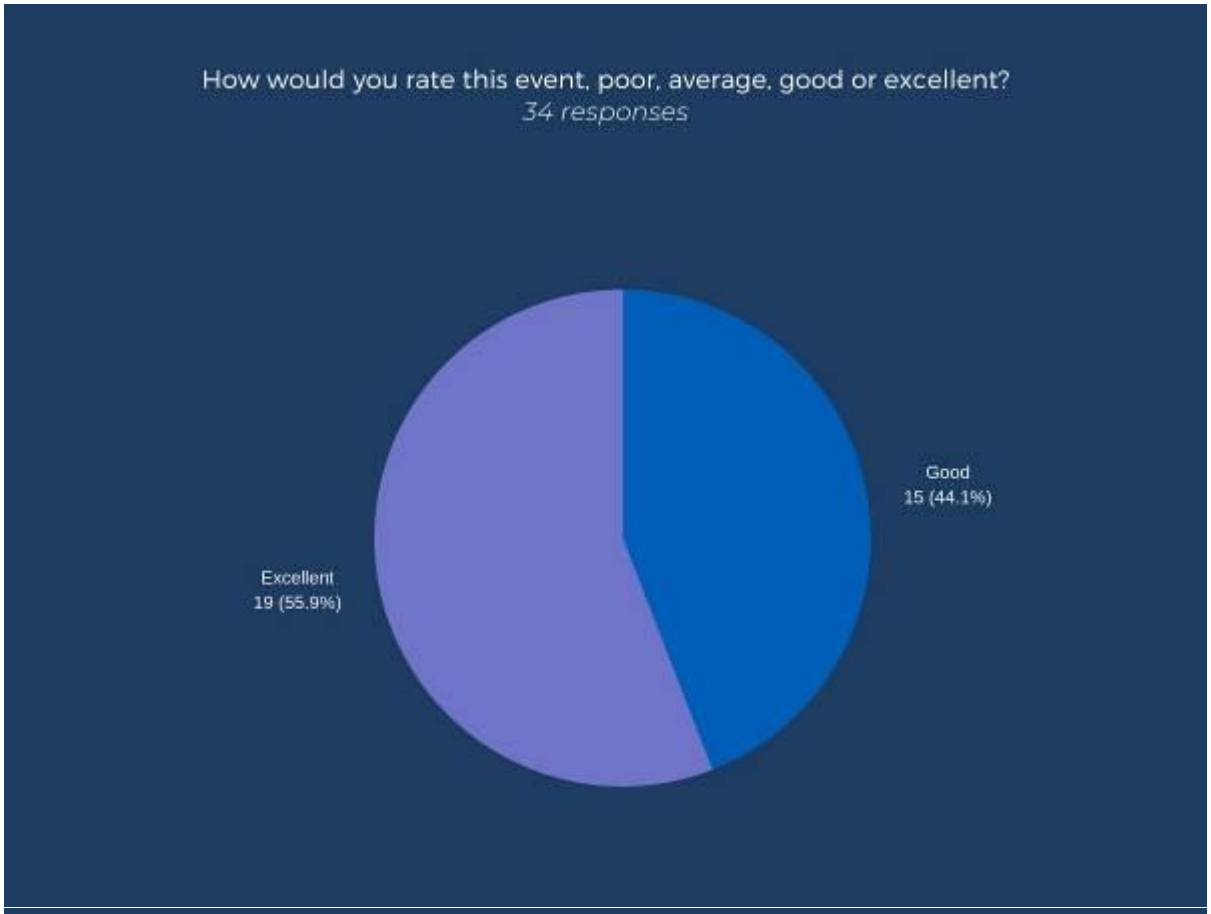
34 responses

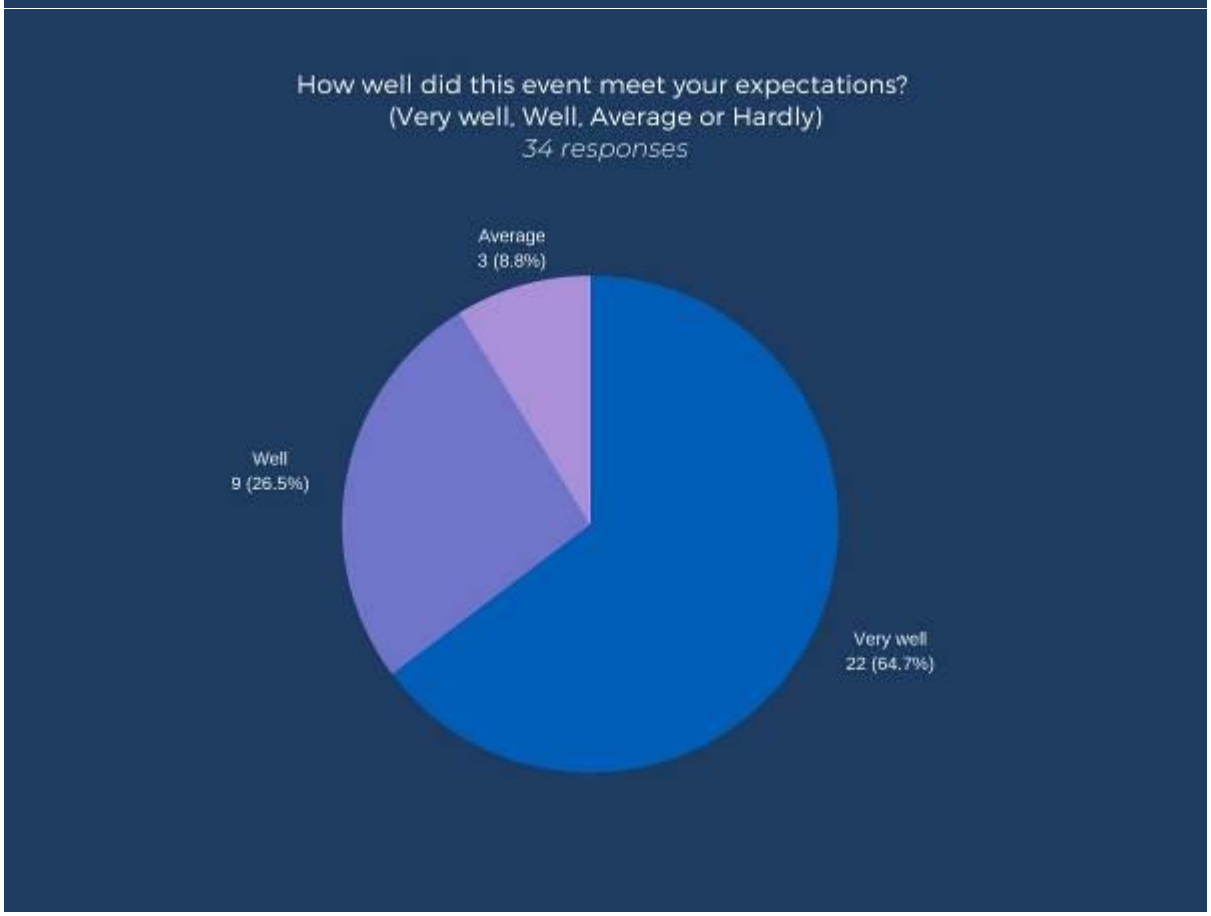


Considering your overall experience, with 0 being the least likely and 10 being the most likely, how likely are you to recommend this event to your friends or colleagues?

34 responses

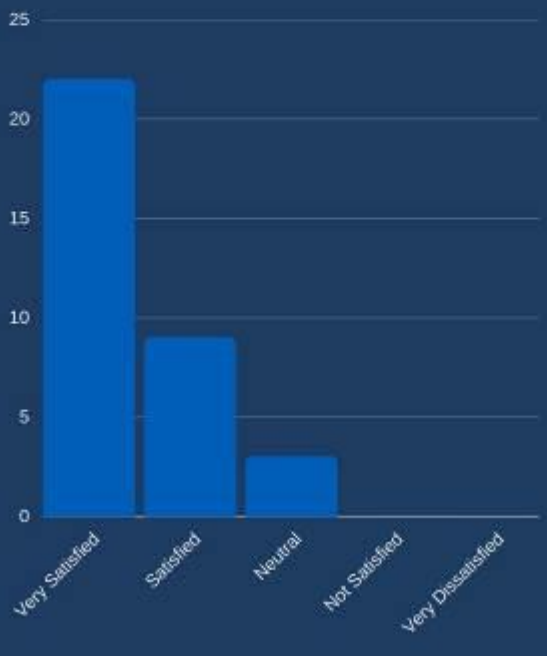



How would you rate this event, poor, average, good or excellent?
34 responses
Good
15 (44.1%)
Excellent
19 (55.9%)

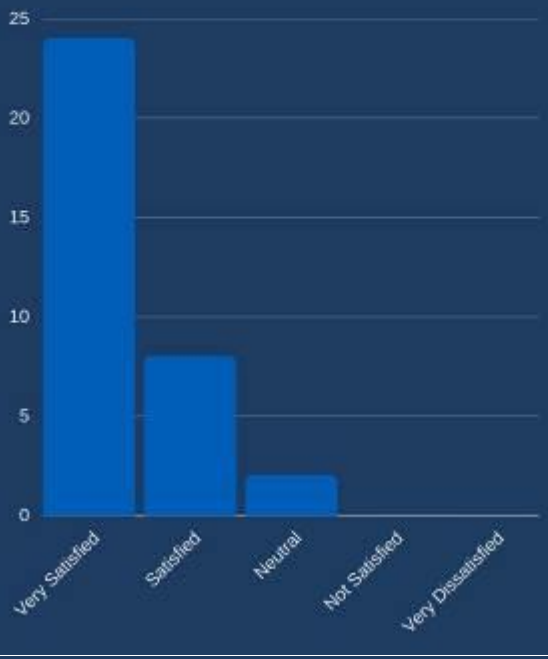

How well did this event meet your expectations?
(Very well, Well, Average or Hardly)
34 responses
Average
3 (8.8%)
Well
9 (26.5%)
Very well
22 (64.7%)

Would you attend this event again in the future? (Yes or No)
34 responses

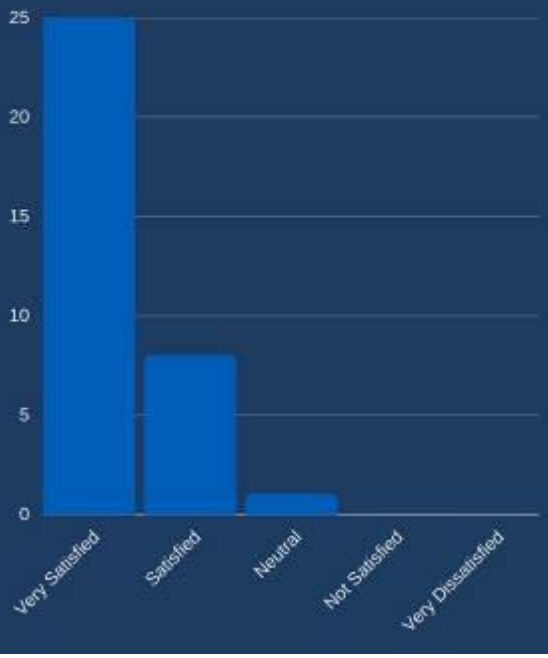
How would you rate the talk How the National Aspergillosis Centre came to be?
(Very satisfied, satisfied, neutral, not satisfied, very dissatisfied.)
34 responses



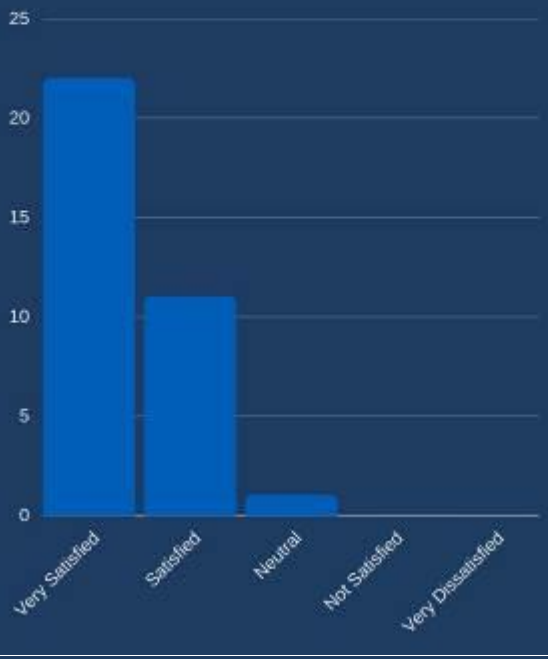
How would you rate the talk Who Gets Aspergillosis?
(Very satisfied, satisfied, neutral, not satisfied, very dissatisfied.)
34 responses



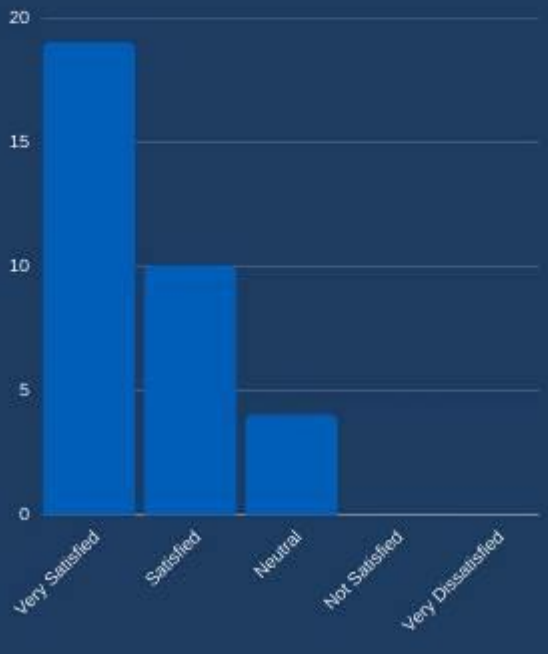
How would you rate the talk How Do We Detect Aspergillosis?
(Very satisfied, satisfied, neutral, not satisfied, very dissatisfied.)
34 responses



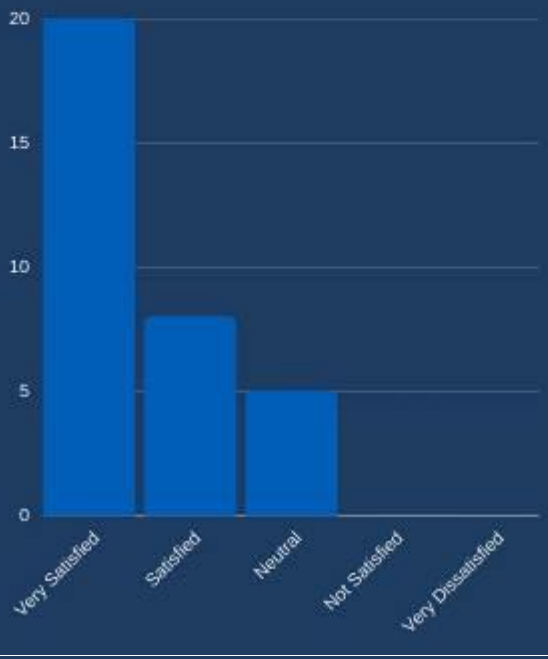
How would you rate the talk Are Antifungal Drugs Complicated To Use?
(Very satisfied, satisfied, neutral, not satisfied, very dissatisfied.)
34 responses



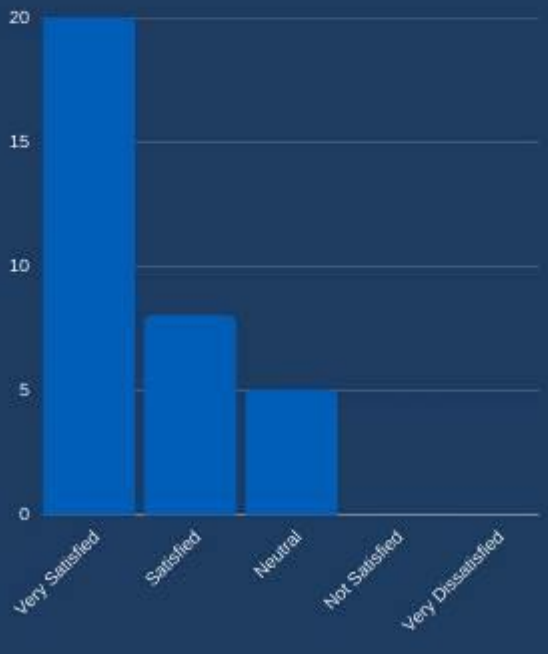
How would you rate the talk Helping Patients Live With Aspergillosis?
(Very satisfied, satisfied, neutral, not satisfied, very dissatisfied.)
33 responses



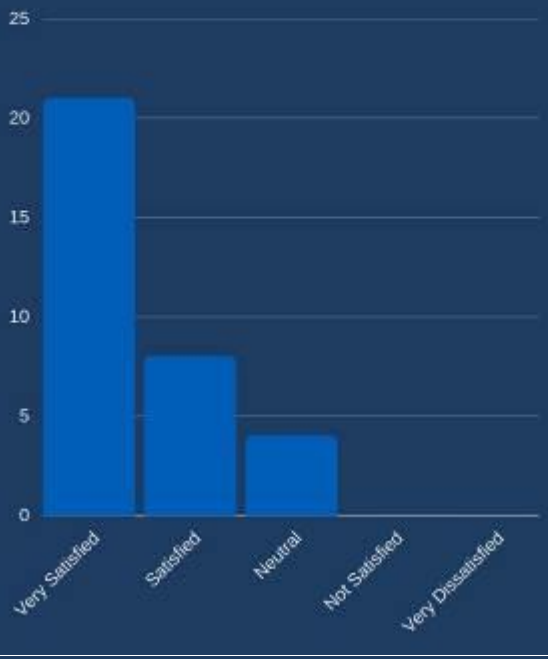
How would you the rate the Patient Stories on Living With Aspergillosis?
(Very satisfied, satisfied, neutral, not satisfied, very dissatisfied.)
33 responses



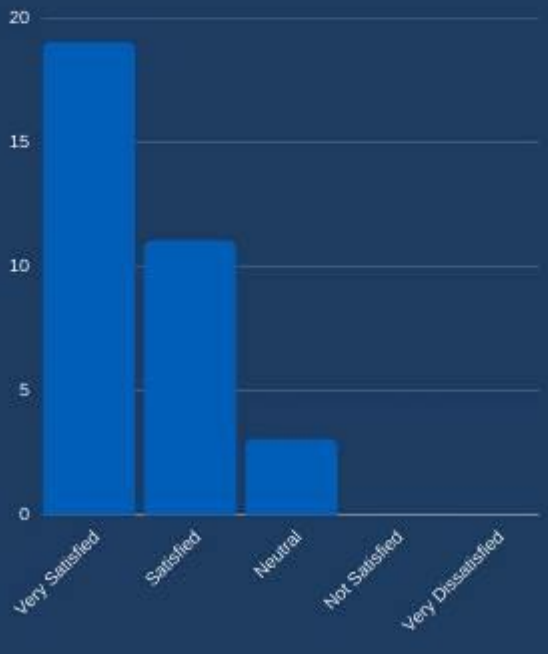
How would you the rate the Patient Stories on Living With Aspergillosis?
(Very satisfied, satisfied, neutral, not satisfied, very dissatisfied.)
33 responses



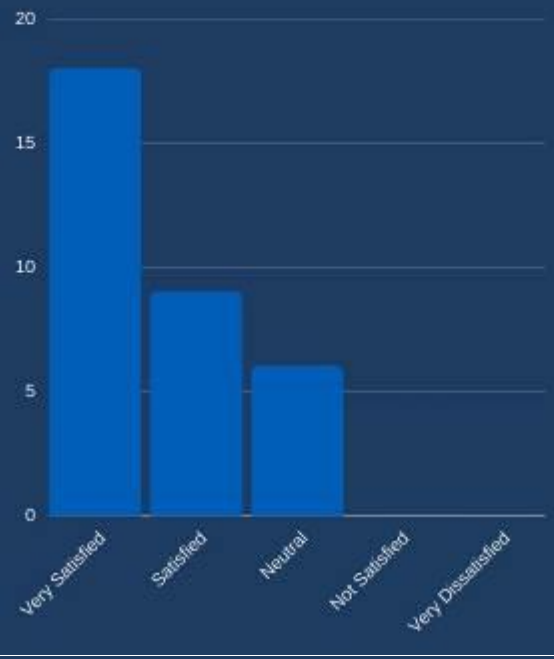
How would you the rate the talk on MFIG Research In Manchester?
(Very satisfied, satisfied, neutral, not satisfied, very dissatisfied.)
33 responses



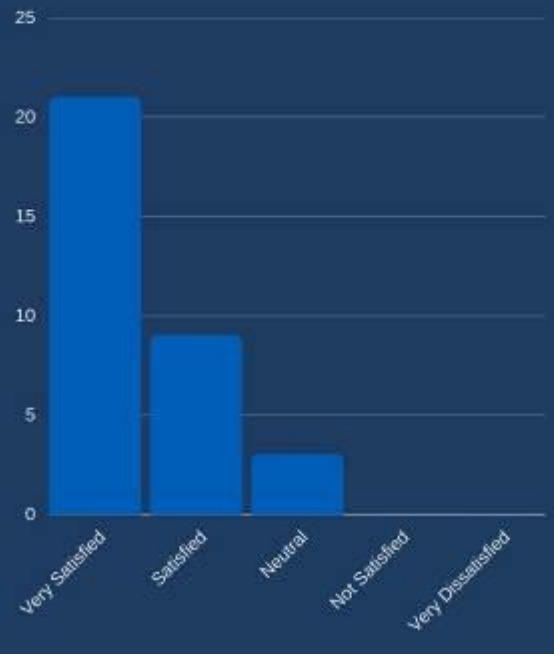
How would you the rate the talk by the MRC Centre for Medical Mycology, Exeter?
(Very satisfied, satisfied, neutral, not satisfied, very dissatisfied.)
33 responses



How would you the rate the talk by the European Lung Foundation?
(Very satisfied, satisfied, neutral, not satisfied, very dissatisfied.)
33 responses



How would you the rate the talk by the NAC Cares Team?
(Very satisfied, satisfied, neutral, not satisfied, very dissatisfied.)
33 responses



What did you like about the event? (Free text response)
24 responses

All

It's was good.

Mix of research, clinical and patient experiences. (I missed the beginning so put neutral for talks I missed above).

Informative presentations.

Every thing.

Easy to understand speakers.

Interesting and informative.

Information about my disease.

Variety of speakers abs short sessions.

NA.

Availability of information.

Brings patients from many different countries, we can listen to many top experts in aspergillosis and hear what progress is being made with fungal drugs and treatments.

Dieron información sobre investigaciones nuevas (Translation: gave information about new research).

What did you like about the event? (Free text response) Continued...
24 responses

New knowledge.

I enjoyed the morning session learnt a lot after many years of being a patient.

Information on different types of Aspergillosis, drug explanations. Physio information on use of spacer and importance of chest clearance. Future novel antifungal therapy gave me hope and reassurance that there will be more treatments in the not too distant future.

Information.Although Im struggling to catch what the abbreviations mean.

Clear explanations and information by clinicians and researchers gave me an overall understanding. Plus I didn't feel as isolated.

I attended on on zoom, I found the event, clear and informative. It was so good to know so much research is underway, and so much progress in treatment as well it was also good to watch the morning sessions, which I could not get to , the following day on youtube. It's also nice to ask questions of such knowledgeable presenters and get answers that make sense. In my asp. journey so often I have heard evasive replies to questions I have posed to clinicians, as their knowledge base had very little about fungal infections, or allergies.

Topics exposed.

Accessible.

Knowing you are not alone and there is more being done to help this disease.

What did you not like about the event? (Free text response)

21 responses

Nil.

Hurry.

Could have had more breaks? Wonder if some patients found it heavy going. Felt there could have been more questions / discussion from audience, but people weren't very forthcoming so maybe not.

None.

Nothing.

Technical issues with presentations.

All relevant.

Technical problems, attendees not on mute interrupting speakers.

Nothing really.

NA.

What did you not like about the event? (Free text response) Continued...

21 responses

Presentation of information in English

There wasn't anything I disliked about the event.

Fue muy larga la sección de comentarios de pacientes. (Translation: The patient comments section was very long.)

Interaction.

Not able to stay for talks after the Pharmacist.

The researchers talks were difficult to hear.

I only saw the first half up to 12.00pm the talks seem to go quickly and I couldn't make enough nots.

Nothing.

Not enough time for questions.

Nothing.

What topics would you like to see covered at future events? (Free text response)

17 responses

Yes.

More sessions led by patients. Future research priorities. Maybe Q&A with patient questions submitted in advance.

Novel diagnostics and treatment options.

As is.

Latest research updates.

Gamma Interferon & Pulmonary Rehabilitation.

More on how to live with aspergillosis while keeping fit.

AMR , AIR /WATER TREATMENT.

What topics would you like to see covered at future events? (Free text response) Continued...

17 responses

Candida.

Micosis invasivas.

New fungy infection.

Updates on research and new treatments. Maybe a brief talk on the breathing techniques that can help. Is there a strategy for a speciality Aspergillosis clinic closer to South Wales.

I'm not sure as Im not that familiar with it all yet.

Not sure at the moment as still digesting information.

Treatment improvement in practice clinically. .Patient experience of getting better, managing conditions.

Some information on SAFS and how that can progress.

Any other comments (Free text response)

15 responses

Good luck.

It was a great day!

None.

Excellent day.

I answered neutral to the talks I did not attend.

Someone who can help with a patients mental health issues.

An excellent day. Quite tiring but well thought out.

NA.

Subtitles in Russian.

Any other comments (Free text response) Continued

15 responses

Not

Thank you for the information.

Is there a video of this webinar? If yes, can you send a link, please.

An informative day, I didn't really know before how the NAC was set up. The medical talks were all very informative. I will rewatch quite a lot of today's talks.

I couldn't comment on all the talks as I only saw the morning session.

Thank you for the information.