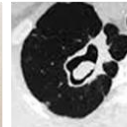
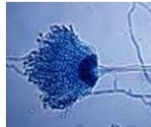
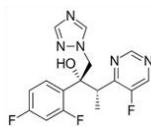


NHS National Commissioning Group – Highly Specialised Services Chronic Pulmonary Aspergillosis National Service



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1. Annual Service Overview and Highlights

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

During the 2023/24 period we continued to focus on providing exemplary care in the management of CPA. While our priority was to ensure quality care for patients with CPA already under our care, we also strived to raise awareness of CPA among clinicians nationwide to enhance recognition and early diagnosis of this under-recognised disease.

A total of 101 new patients from England and Scotland (plus a further 3 patients from Wales) were assessed at the NAC and diagnosed with CPA between 1st April 2023 and 31st March 2024. This was an increase from 72 in 2022-2023. A total of 209 new patients were referred and assessed for all forms of aspergillosis. We believe that the numbers of new CPA referrals have increased due to a combination of patients being increasingly diagnosed post-pandemic and our efforts to raise awareness for CPA among clinicians and the public. In the year 2023/24, we reached a number of CPA patients comparable to the number pre-pandemic. The average waiting time from referral to being seen was 54.6 days.

At the end of March 2024, we had 311 patients from England and Scotland on service. Twenty-four patients were discharged from service as they were stable off antifungal treatment and had no active CPA. Many of these patients are discharged from the commissioned service but remain under our care in the tertiary MFT Aspergillosis service. There were 30 deaths, a number lower than the previous year.

Remote advice and guidance have become a major part of our work and a reality post-pandemic to which we have adapted by developing our National MDT forum, which was first established in September 2021. This gives the opportunity to external consultants to access NAC expertise and obtain advice on CPA diagnosis and management. Medical, nursing, pharmacy, physiotherapy and mycology expertise is available to all external clinicians at every MDT meeting. We discussed 71 such external cases in the MDT in 2023/2024 (up from 51 in 22/23). 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 the MDT, we have also continued to provide remote written advice and guidance in 56 cases (up from 52 in 22/23). This method of advice was initiated during the pandemic to allow patients to remain closer to home for treatment in the light of the pandemic and travel restrictions.

The main patient outcome we monitor and report is response after 6 months of antifungal treatment. We monitor this by assessing clinical response, radiological response on a chest CT scan and Aspergillus serology.

We have maintained our out-patient follow up activity using a hybrid of video consultations, telephone consultations and face to face appointments. Hospital admissions remained low

compared to pre-pandemic years. This is mainly due to the more structured MDT approach that facilitates IV antifungals in the community through our OPAT service or in local hospitals. Previously, patients would be admitted for IV antifungals; this is no longer necessary in most cases. In addition, bronchial artery embolisations can now be undertaken via our interventional radiology clinic in a semi-elective process when possible, again avoiding admission to hospital.

The NAC continues to be under the governance structure of the Managed Single Service (MSS) for Infectious Diseases for Manchester University NHS Foundation Trust (MFT). Dr Chris Kosmidis was appointed as Clinical Lead in August 2024 for a three-year term. Chris Harris has retired from her position as NAC Manager.

Our CARES team (Community, Awareness, Research, Education, Support) continues to support our patients as we emerge from the pandemic. The team have provided support to patients via several platforms including telegram group communication, monthly educational meetings, weekly social support meetings, health and wellbeing meetings and our quarterly newsletter. The team have moved from Zoom to Teams meetings in 2023. We have continued to seek patient feedback. We continue to see significant activity through our social media channels (Facebook, Twitter and LinkedIn). We additionally have taken a new focus on our patient and carers website which is growing in usage. In order to support patients better, the CARES team utilises MyMFT, an integral part of our Trust's new electronic patient record 'Hive' powered by Epic. MyMFT is the patient portal giving 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 that is essential for the long-term management of patients with complicated fungal disease such as CPA. The MRCM has UKAS accreditation and both the MRCM and the NAC have European Confederation of Medical Mycology centre of excellence diamond award status. 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 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 (a technique that increases the likelihood of detection of aspergillus in sputum thereby affecting treatment decisions) and Aspergillus IgG determination by lateral flow assay (a rapid diagnostic test). The MRCM is pivotal in new drug development studies and susceptibility testing.

The NAC and MRCM have continued their reputation in international research with 20 publications relating to aspergillosis diagnostics and treatment. We remain in the forefront of scientific developments in CPA through our research output and clinical trials of new antifungal treatments. We have been awarded a grant for a randomised controlled clinical trial of immunotherapy in CPA by the NIHR Research for Patient Benefit Scheme (£251,000). Recruitment has opened in June 2024 and will last for 48 months with an aim to recruit 50

participants. The team delivers educational lectures and seminars nationally and internationally.

A major focus this year has been on safe prescribing of antifungal medications. An important audit of drug interactions was conducted this year and a new policy on safe co-administration of azoles with interacting medications is being implemented.

Our main aim for the next year is to further improve patient safety and experience by taking advantage of the opportunities that have emerged as a result of the pandemic, such as the use of technology in patient monitoring and collaboration with referring consultants (e.g. use of video conference software and of the new paperless electronic medical records in our Trust enabling patients to participate more actively in their care). We aspire to bring quality of life assessments to the forefront of CPA management by streamlining the recording of patient-reported quality-of-life scores so they can affect clinician decisions. An important objective is to increase awareness of the service to consultants in the parts of the country that are under-represented among our new patient referrals. Finally, we aspire to promote research in CPA treatment by exploring the role of new and emerging antifungals while encouraging patient and carer involvement in research.

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, prescription and monitoring 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. While we strive to increase face-to-face appointments and aim to see every patient face-to-face at least once a year, we also take advantage of the available options for remote consultations via video or telephone, for patients who are stable and have good local consultant and GP support. All new patients are booked as a face-to-face consultation. We continue to use remote monitoring of blood tests and sputum by post via a long-established pathway.

On-going long-term management continues to include:

- evaluation of symptoms, quality of life impact and response to medication
- monitoring of antifungal drug levels and side effects
- establishing homecare medication delivery direct to the patient every 2 months
- withdrawing medication when there is no effectiveness as per our agreed clinical pathways

- 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
- referral to thoracic surgery or interventional radiology as needed

Whenever possible, investigations are performed closer to home. We take care to ensure that local consultants (respiratory or infectious diseases specialists) and GPs are kept informed of our plans.

The implementation of our new paperless electronic patient records system (HIVE) in September 2022 has meant a steep learning curve for all members of the team, regarding request of investigations, clinic letters and communications with referring teams and patients. Members of the team stepped up and facilitated training within the team. Going forward, we are aiming to take advantage of the opportunities offered by this new EPR system, such as improved patient experience and audit.

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. All new CPA diagnoses are discussed and ratified in our weekly MDT meeting.

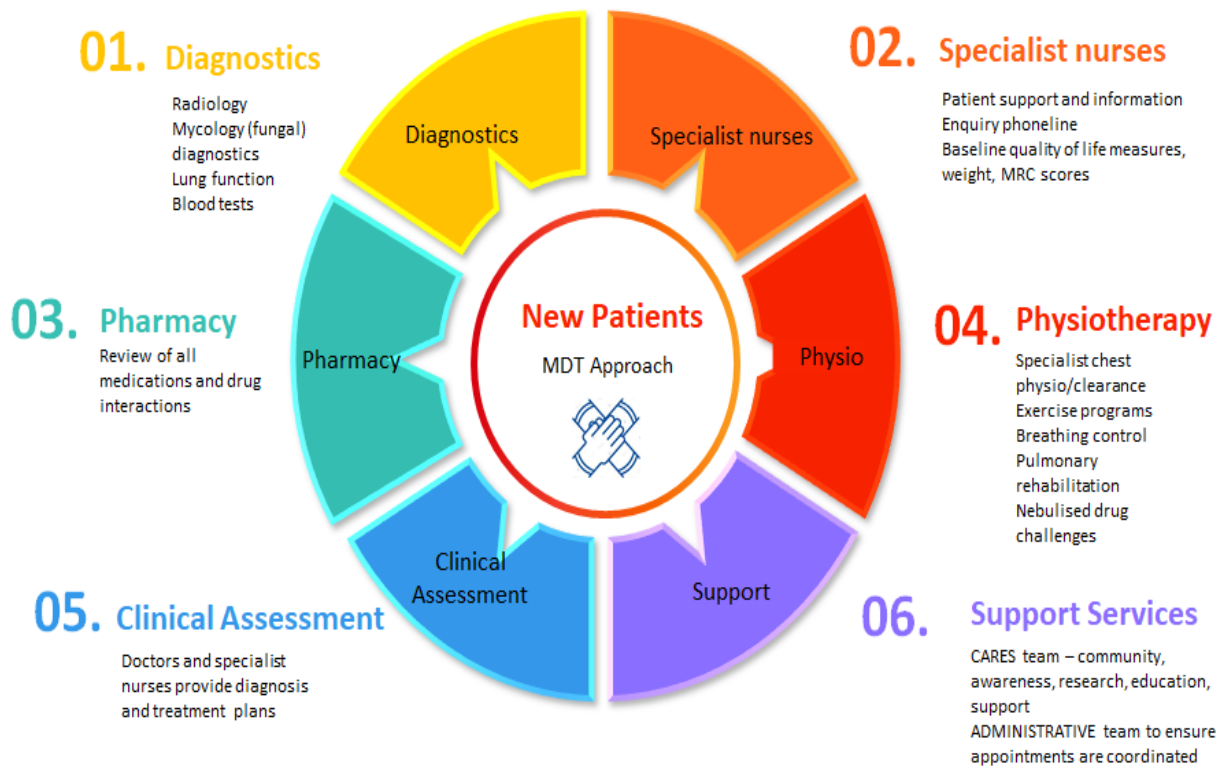
In addition to our out-patient clinics we also deliver short-term inpatient care – this includes evaluation of disease, intravenous therapy, bronchial artery embolisation, surgical resection, training in intravenous line management and delivery of iv antifungals in the community (OPAT). Hospital admissions have reduced as a result of our structured MDT approach and involvement of local and referring consultants, enabling treatment closer to home with our supervision, or involvement of our OPAT team without the need for hospital admission. Over the years our OPAT team has accumulated significant experience in the administration of antifungals in the community.

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.

This report details the outcomes over the time period 1st April 2023 to 31st March 2024.

Schematic diagrams of NAC services

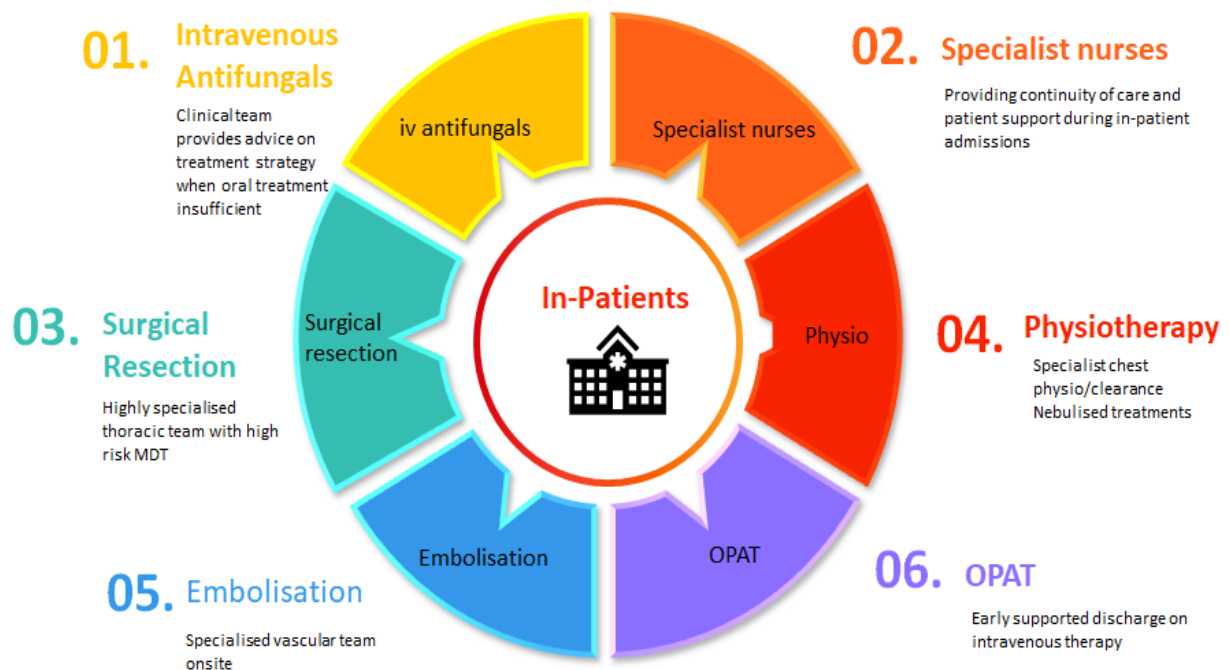
NEW PATIENT SERVICES



FOLLOW UP SERVICES



IN-PATIENT SERVICES



2.2 Workforce infrastructure and sustainability

Clinical and administrative personnel

The following clinical and administrative personnel provide support for the NAC:

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 (3 PAs)
Dr Huw Ellis, Consultant in Respiratory Medicine (1.5 PAs)
Dr Riina Richardson, Honorary Consultant in Mycology
Mrs Christine Harris, NAC manager (100%) – retired July 2024
Mrs Jenny White, Lead Specialist Nurse (85%)
Miss Niamh Duffy, Specialist Nurse (50%)
Mrs Lincy Cyriac, Specialist Nurse (50%)
Ms Lindsey Caudwell, Band 3 HCA (100%)
Mr Philip Langridge, Senior Specialist Physiotherapist (100%)
Ms Mairead Hughes, Specialist Physiotherapist (50%)
Dr Hana Barzinji, Clinical Education Fellow (30%)
Dr Adeola Akindele, Clinical Fellow (30%)
Dr Annabel Choyce, Clinical Fellow (30%)

Dr Sardar Islam, Clinical Fellow (30%)
 Ms Fiona Lynch, Specialist Senior Pharmacist (40%)
 Ms Zainab Zulfikar, Specialist Senior Pharmacist (40%)
 Dr Graham Atherton, Dr Graham Atherton, CARES Service Lead (100%)
 Mrs Lauren Amphlett, Communications Specialist (100%)
 Dr Elizabeth Bradshaw, Medical Writer and Web Manager (100%)
 Carmel Marshall, B5 Infectious Diseases and NAC Directorate Support Manager (50%)
 Anna Mikolajczak - Vacant (from 14th February) B3 Waiting List Clerk (50%)
 Letitia Blake B3 Administration and secretarial support (50%)
 Vacant (from 29th May 2023) B2 Administration and secretarial support (50%)
 River White B2 Administration and secretarial support (50%)

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

The total referrals, patient caseload, in-patient stays and procedures for 2023/2024 are shown below:

	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Final for 23/24
Referrals	9	19	20	18	12	11	23	30	20	20	14	13	209
New CPA diagnoses	6	10	8	8	9	9	12	9	10	7	10	3	101
New Patients Advice and guidance	1	3	9	6	3	1	4	7	9	6	3	4	56
Patients discussed in MDT by external clinicians	5	6	3	9	10	8	3	5	6	3	4	9	71
Embolisations	2	1	0	0	0	0	0	0	0	0	1	0	4
Surgical Resection	0	0	0	0	0	0	0	0	0	0	0	0	0
Caseload - Band 1	77	76	76	75	76	78	80	82	79	76	78	81	81
Caseload - Band 2	202	201	207	210	214	218	218	221	223	223	223	223	223
Caseload - Band 3	9	8	8	8	8	8	8	7	7	7	7	7	7
Occupied Bed Days	20	10	0	0	0	4	0	0	0	0	4	0	38
Outpatient - Follow-Up Attendances	47	87	89	56	74	117	79	95	98	92	94	102	1030
IV Homecare (OPAT)	0	0	0	0	0	5	3	0	0	0	0	0	8
Inpatient Discharges	2	1	0	0	0	1	0	0	0	0	1	0	5
Discharged from Service	2	3	1	3	1	0	3	3	3	3	1	1	24
Patient Deaths	0	5	2	2	0	3	1	2	3	4	4	4	30

* The NCG funds patients from England and Scotland only

** Appendix 1 shows the clinical definition of case bands

Referrals

There was a total of 209 referrals from England and Scotland during the year 2023 to 2024 (up from 167 in 22/23) that underwent clinic consultation by the service for all forms of Aspergillois. 101 (47%) of these received a confirmed diagnosis of CPA (up from 72 in 22/23). There were a further 5 patients from Wales of which 3 were confirmed with CPA. All new patients are discussed at our weekly MDT to ensure a unified agreed diagnosis and management plan. The number of referrals and the number of new CPA patients increased compared to 2022/2023; the proportion of referrals with a diagnosis of CPA remained stable this year. The number of new CPA patients has continued to increase following the significant reduction during the pandemic and has now reached pre-pandemic levels (we had 104 new CPA cases in 2019-2020).

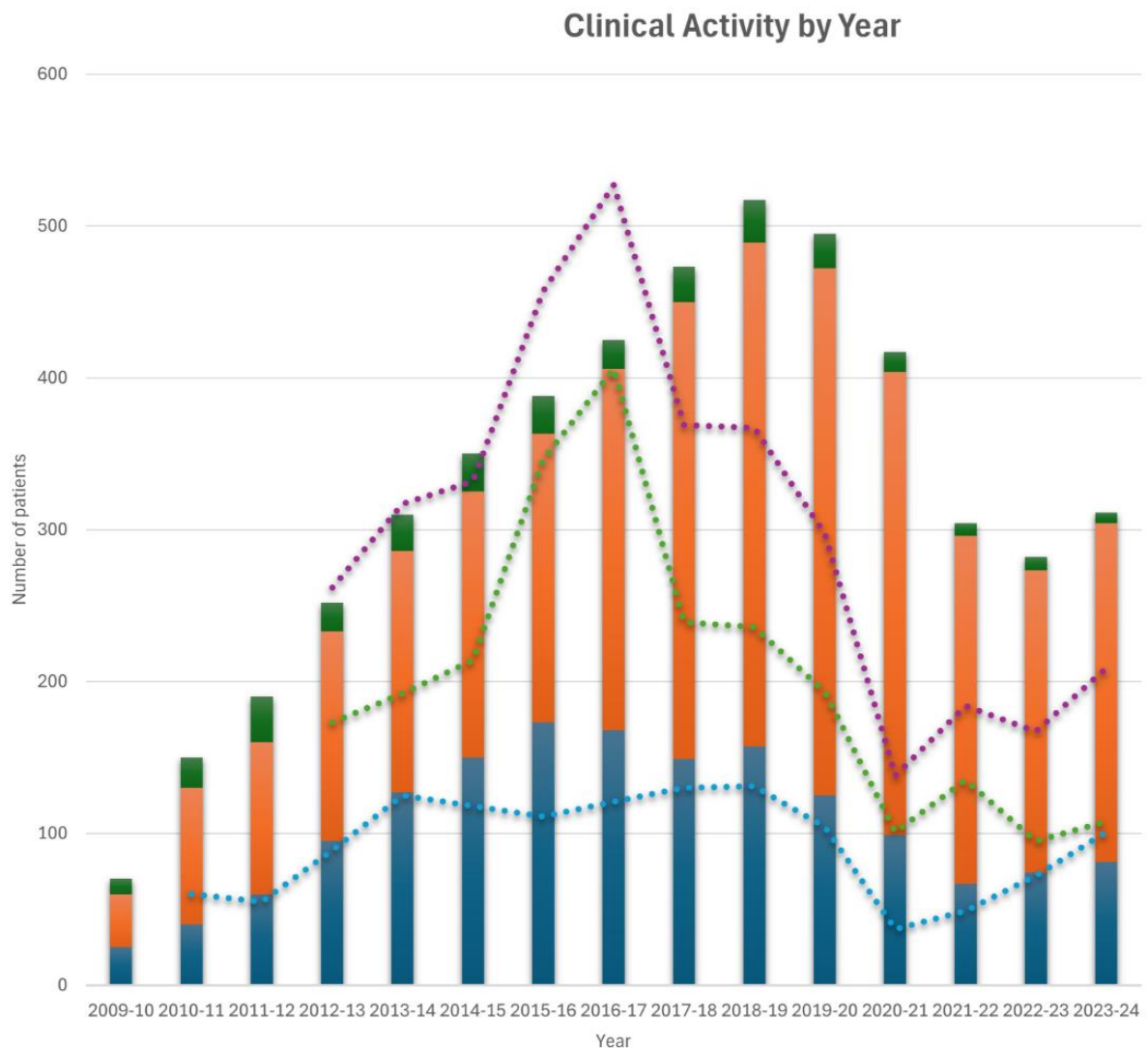
Our National MDT forum, established in September 2021, gives the opportunity to external consultants to access NAC expertise. We discussed 71 such external cases in the MDT in 2023/2024 (up from 51 in 22/23). The National MDT allows physicians from all over the UK to

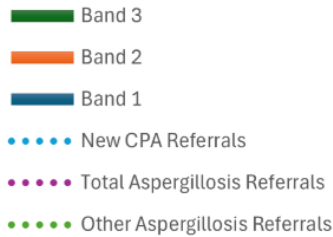
dial into our MDT using MS Teams to share diagnostics and imaging and allow a consensus diagnosis and management plan.

In addition to the MDT, we have also continued to provide remote written advice and guidance in 56 cases (up from 52 in 22/23). This method of advice was initiated during the pandemic to allow patients to remain closer to home for treatment in the light of the pandemic and travel restrictions.

We are reporting our MDT and written advice and guidance data in our monthly NHSE data.

NAC Referrals and Caseload 2009 to 2024





Out-patient waiting times

The mean time from referral to clinic consultation was 54.6 days (range 7-199 days).

Geographical location

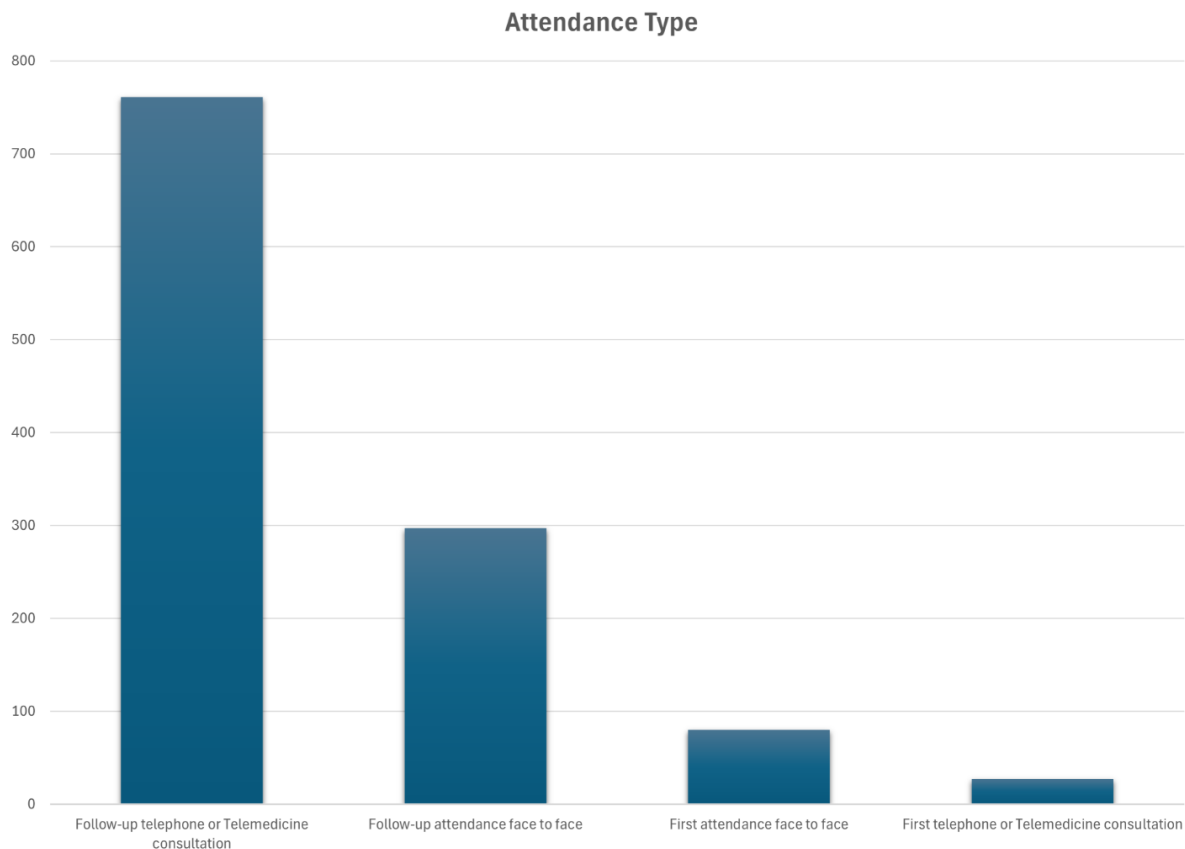
Appendix 2 displays maps of the geographical locations (postcode areas) of the new patient referrals and all patients on service. Historically more patients from the North-West of England were seen in the service and this continues; however, we do follow patients from most parts of the country (Appendix 2, Graph 1). New CPA referrals for 2022/23 originated from various parts of the country including the South and East of England (Appendix 2, Graph 2). Our new national MDT, established in September 2021 enabling consultants to request advice remotely, has facilitated engagement with the service by consultants in remote areas who would not have otherwise referred the patients to the NAC. Appendix 2, Graph 3 shows the distribution of patients brought by external consultants to the MDT. Most parts of the UK are represented, but notably many cases were discussed from Northern Ireland, Wales and the Southwest of England. We raise awareness for CPA and the NAC among consultants and GPs via our National MDT, social media, educational sessions such as World Aspergillosis Day, and attendance at Respiratory and Infection scientific meetings.

Patient Caseload

At the end of March 2024, 311 patients from England and Scotland were on service with an additional 12 patients from Wales, 2 from Northern Ireland, and 2 from the Isle of Man. Patients with CPA are banded according to disease severity, impact on functional ability and presence of antifungal resistance (Appendix 1).

During 2023/24 there was an increase in patient numbers (See NAC referrals and caseload, above). This increase is due to the increased number of referrals year on year since the pandemic. The numbers discharged are comparable (24 in 23/24 from 33 in 22/23). Numbers of deaths have reduced (30 in 23/24 from 44 in 22/23). Patients discharged from service as they have no active CPA may remain under the care of our team but outside the commissioned service. As the relapse rate of CPA is around 20%, some patients may re-enter the service.

The ratio of face to face to remote consultations has remained stable at around 40%. Out of more than 1000 outpatient clinic encounters, the attendance type is shown in the graph:

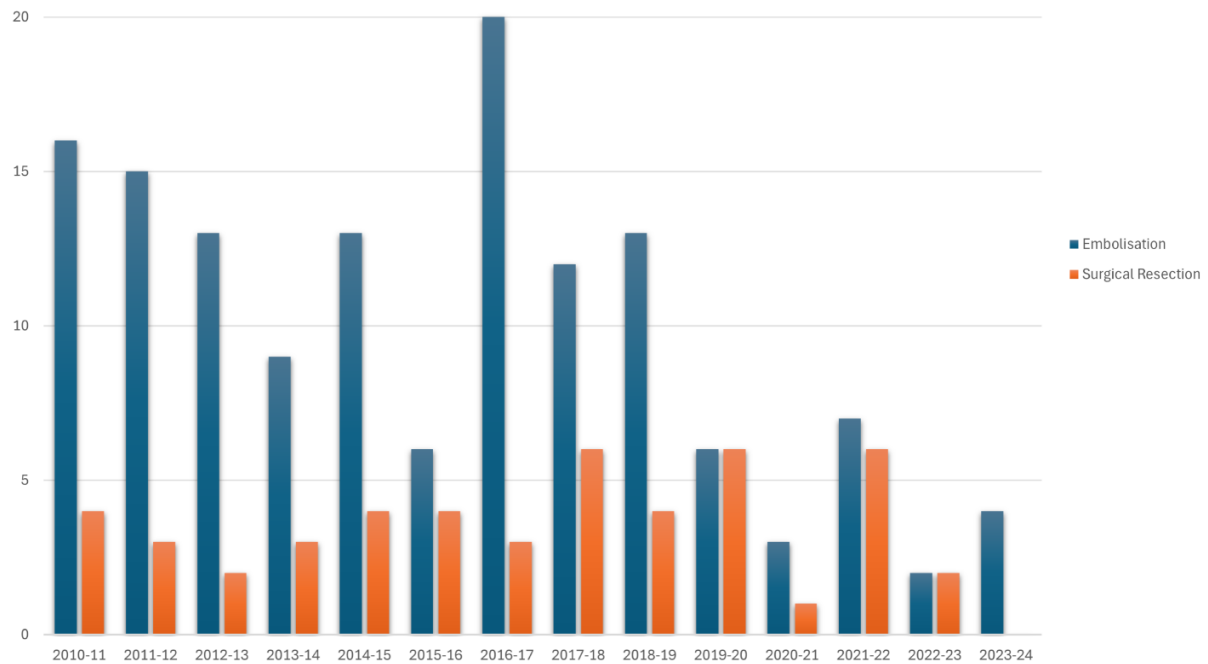


We currently see 42 patients in our weekly CPA clinic. There are at least 2 consultants at any time in the clinic, along with trainee doctors, Specialist Nurses, a Healthcare Assistant and a Physiotherapist.

Our weekly CPA MDT has now expanded and now lasts for 2 hours to accommodate discussion of all new CPA cases, 6-month drug trials, complicated cases and cases brought by external consultants. There are up to 15 patients discussed each week, with 2-3 external cases.

In-Patient Hospital Activity

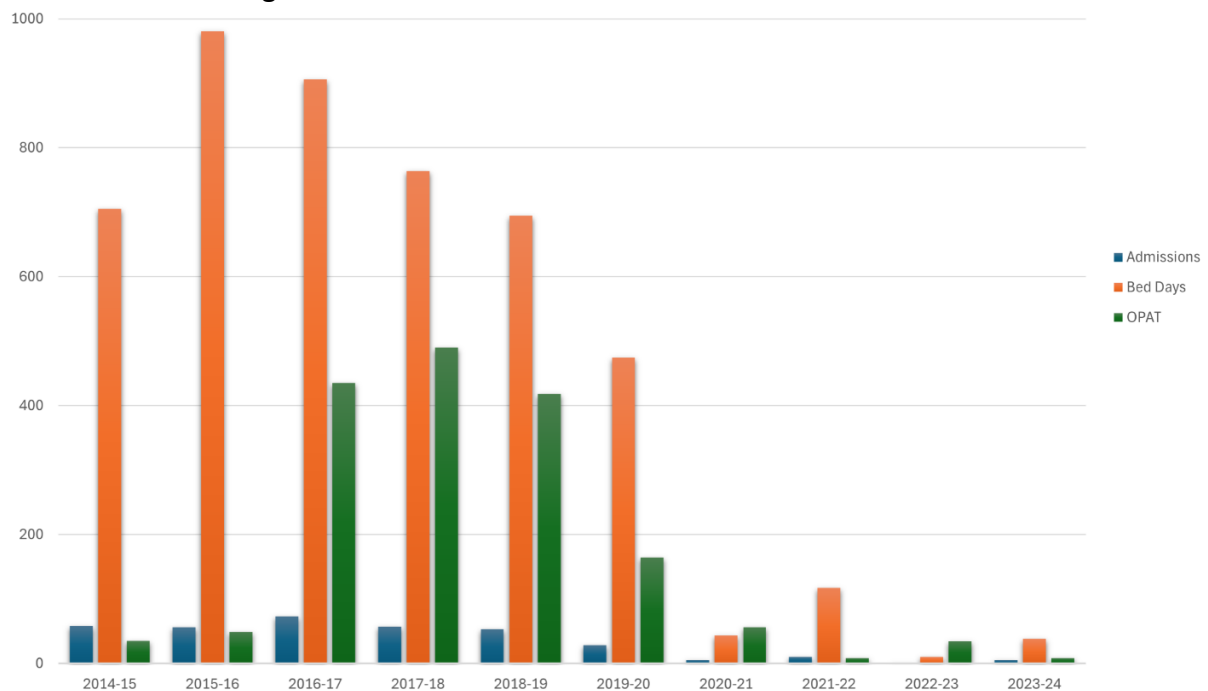
We have seen a reduction in in-patient activity this year to 5 bed days. The reduction in in-patient activity is the result of coordination with our OPAT service to enable IV antifungals in the community, of our close communication with the parent teams, usually via our National MDT which has made possible their admission closer to home with our remote advice. Four patients had embolization, no-one had surgical resection, and 8 had intravenous antifungals. The numbers of patients who underwent embolization and surgical resection in the NAC is shown below.



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. The OPAT activity during the financial year 2023/24 is shown below.

Admission data are given below:



2.4 Antifungal Trial Data

We continue to use n-of-1 trials for voriconazole, posaconazole and isavuconazole. Itraconazole is also given for treatment of CPA, but we do not record these outcomes for commissioning purposes as itraconazole is prescribed in primary care.

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 St George’s Respiratory Questionnaire 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), as has been agreed with NHSE. We still recognise the importance of measures of quality of life and try to collect this data when possible. Since March 2024, we have also been collecting QoL data in the form of the CAT score, as part of a quality improvement project. We collect QoL data at the beginning of the drug trial, at 4 and at 6 months. We have incorporated QoL assessment in our new EPR to enhance clinical decisions and patient experience.

Overall, success of antifungal therapy was 57%. Failure of treatment, defined as lack of clinical improvement and/or adverse events of the medications, was documented in 27%. Thirteen percent died during the course of treatment and in one patient the assessment was pending. 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 2023-2024								
Outcomes	Posaconazole		Isavuconazole		Voriconazole		overall	
		%		%		%		%
Success	7	54	4	67	6	55	17	57
Failure/ADR	3	23	1	17	4	36	8	27
Death	3	23	1	17	0		4	13
Pending	0		0		1	9	1	3
Total	13		6		11		30	

Trials of posaconazole/isavuconazole/voriconazole 2022-2023						
Outcomes	Posaconazole		Isavuconazole		Voriconazole	
		%		%		%
Success	10	58	11	85	8	73
Failure	2	11	2	15	0	0
Death/ADR	5	29	0	0	3	27
Total	17		13		11	
Pending	4		2		12	

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	

2.5 Intravenous antifungal therapy

Intravenous antifungal therapy is most often used when azole therapy has failed, resistance has developed or around surgical resection. Two patients received a total of 34 days of intravenous treatment with micafungin via our OPAT service, whereas another 7 patients received IV antifungals by their local teams.

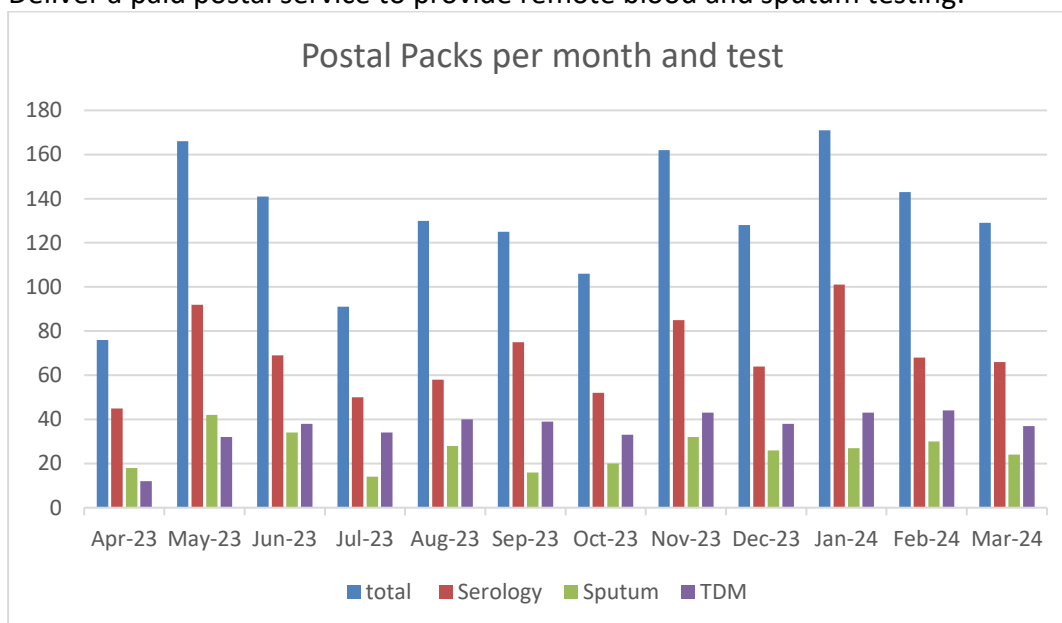
2.6 Antifungal prescribing and expenditure

Antifungal expenditure has fallen significantly since Posaconazole came off patent and generic brands become more widely available in 2021. This is similar to 2017 when voriconazole came off patent. Isavuconazole costs have remained stable since the introduction into our commissioning pathway in 2016 (see Section 13).

3. Specialist Nurse Service

The NAC has a team of highly specialised and dedicated nurses. The service currently has 3 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 Wythenshawe 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 specialist nurse continues to independently prescribe treatment. Specialist nurse has completed the NMP course and is awaiting sign off
- Senior specialist nurse has been involved in the development of national guidelines.
- Senior Healthcare Support Worker (HCSW) supports patients in the outpatient clinic appointments, in particular new patient appointments
- Senior HCSW has worked closely with the medical director to explore alternative patient outcome questionnaires and completed them in clinic and over the telephone at starting antifungal therapy, at 4 months and at 6 months
- The nursing team have received very positive feedback from the surveys sent out post clinic consultations, the team will aim to maintain this standard, feedback included below:

It is good to have on line consultations as it would be very difficult to go to Manchester.

The staff. Where very. Friendly. Explain. Everything. And didn't rush me. Very pleased. With the service. I was given Thank you

Detail of the. proposed care plan are to be given via telephone on Friday, 8 December. Staff were very friendly and helpful.

It was my first time at Wythenshawe hospital the nurse and staff was caring and kind looked after me and I didn't wait long to be seen

I have more understanding of the condition I have and the information booklet I was given by Jennifer was very helpful thank you.

No, except to thank Jenny for her help

Pleased with appointment

Niamey emailed me back as promised with query regarding my treatment

From the Nurse. Physio. Blood woman ecg and the xray department I was treated really well everything explained in full. Lovely team at the Aspergillious centre.

I know all I need to know thankyou

THANK YOU TO THE SPECIALIST NURSE & THE NURSE WHO TOOK MY BLOODS. THEY MADE ME VERY COMFORTABLE. ALSO VERY BIG THANKS TO GETTING ME FITTED IN TO MY APPOINTMENT AS I KNOW EVERYBODY IS SO BUSY.

Reviewed current status of condition and medication. Collective agreement on next steps to include blood samples for analysis and CT scan to be organised by local respiratory medicine team . Happy with answers to questions raised , reassured and appreciate NAC support.

Everything about my visit was efficient & professional. From the appointment time/date to reception, the HCA's & my consultation. I'm grateful for the care and attention I received.

The NAC nursing service challenges in 2023-2024:

- 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.

Developments for the nursing team 2024-2025:

- With the implementation of the new electronic system continue to explore data collection and analysis
- Senior specialist nurse has commenced a masters module, with an aim to enhance knowledge and improve consultation skills. This will also enhance the nursing team skills as knowledge is passed on.
- Explore research opportunities
- Recruit and train a newly recruited specialist nurse
- Recruit and train a newly recruited senior HCSW

4. Physiotherapy Service

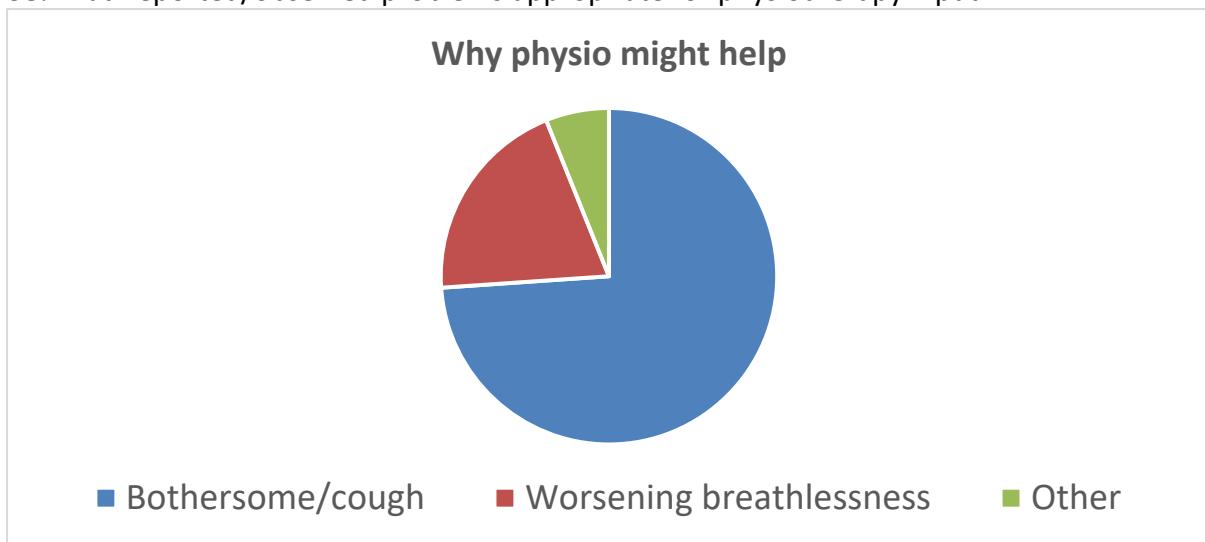
The physiotherapy service is delivered by 1.5WTE specialist physiotherapists with extensive respiratory experience. Both are also independent prescribers.

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.

In 2023/24 the physiotherapy service assessed 158 new patients.

Service development

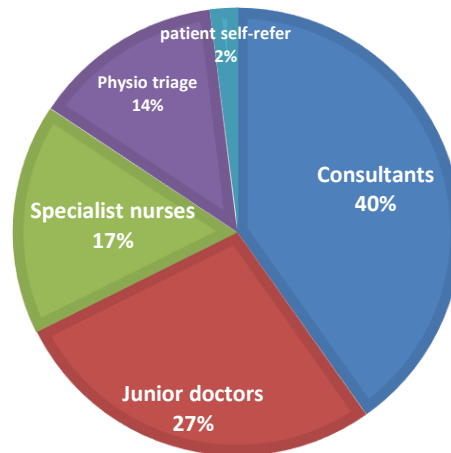
We continue to take physiotherapy students this year for parts of their clinical placements to help consolidate their respiratory skills and to promote the work of the National Aspergillois Centre. Feedback from these students (BSc and MSc level) has been consistently positive. We have also contributed to student education from the wider MDT. We performed a service evaluation to examine physio referral patterns. 300 clinic encounters were examined for potential/ actual physio input. 43% of our patients had previously had physiotherapy input and based on the clinic encounter on the days examined 38% had reported/observed problems appropriate for physiotherapy input.



Examining the referral “gap” from these encounters, 19 face to face, 12 video and 33 Telephone clinic consultations identified problems that would be appropriate for physio intervention but had no ensuing/previous physio referral. Encouragingly there were a spread of referrers to physio from across the MDT. However 21% of those assessed in clinic might have been referred to physio but were not.

REFERRERS

■ Consultants ■ Junior doctors ■ Specialist nurses ■ Physio triage ■ patient self-refer



The referral to physio treatment time varied from 0-134 days (with the longer delays to treatment caused by waiting for other interventions e.g. steroid weans, return to face to face clinic at Wythenshawe, etc).

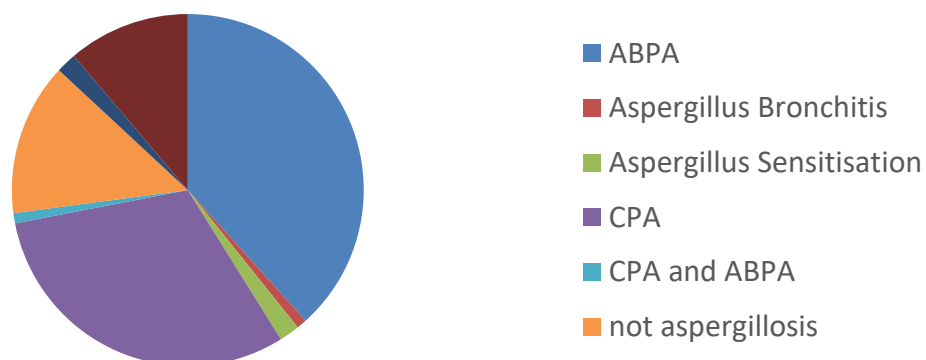
This year no initial interaction with Aspergillus physio was by video. 88% of initial physio assessment/treatment was face to face.

These findings formed the basis for team discussion/ training. We are keen to empower patients to self-refer and our trust's MyMFT app may help facilitate this further.

The challenges ahead

The BTS clinic statement on Aspergillus-related chronic lung disease merely infers value of physiotherapy by describing optimising the general management of asthma and bronchiectasis according to BTS guidelines (including airway clearance.) Our own experience in the National Aspergillus Centre over the last decade has shown that physio interventions are roughly split on a 55:45 basis between ABPA and CPA clinic patients. A larger previous service evaluation by physio of 500 patients showed 42% of those patient

Aspergillus diagnoses of those seen by physio



had a diagnosis of COPD, 26% of those with CPA had a MRC score of between 3-5 yet only 5% of these patients were known to have been referred to pulmonary rehabilitation.

We must continue to extol the virtues of CPA patients referral to appropriate physiotherapy services as well as those with ABPA. Physio takes a problem-solving approach to holistic management of all patients. Regardless of Aspergillus-related diagnosis or co'morbidities our patients receive individualised solutions to the problems they come to clinic with- a real strength of our team and something we take immense pride in.

5. Pharmacy service

The pharmacy service consists of one infectious diseases pharmacist. The primary role involves:

- Reviewing medications and interactions
- Providing advice on drug interactions and adverse effects
- Patient counselling
- Prescribing and management of homecare prescriptions
- Supporting antifungal stewardship within the service
- Safety monitoring with therapeutic drug monitoring/liver function/ECG
- Monitoring medicine expenditure
- Providing external advice on antifungals

Challenges and development opportunities 2024- 2025:

- Currently there is one specialist pharmacist to cover the service and there will be gaps to support the NAC team. Since the merger of the ID single service, further opportunities can be explored to provide cover for leave or long absences from the wider infectious disease's pharmacy team.
- Treatment for CPA has become increasingly challenging with azole resistance and there is need for new antifungals for CPA treatment. The aim would be to support the clinical director with drug formulary application and the wider MDT on managing antifungals.

6. Administrative Team

The admin team is made up of a service manager who manages 4 admin staff whose roles are 0.5 FTE dedicated to NAC. The admin team provide support to patients, prospective patients and other health care professionals. We receive about 40-50 calls a day; the calls vary in nature but cover the following:

- changing appointments
- advice on how to be referred into the service.

- queries on clinical letters or requesting copies.
- transport queries.
- notification from patients they have had local imaging to be imported.

The admin team manage all new referrals into the service (averaging 30-40 per month) ensuring that all the images from local teams and other relevant reports and results are obtained prior to triage. Each new patient who is accepted onto the service is contacted directly by the waiting list clerk to book them into their first appointment. We also schedule all follow ups as well as editing and sending all clinic letters.

The team co-ordinate the NAC weekly MDT for external consultations; in the year to date (Jan to September 23) we have booked over 80 external MDT referrals. The team manage the Patient Tracking List (PTL) for NAC patients within the Trust to ensure they are seen in a timely manner in line with guidelines. The team also complete ad hoc audits to ensure patients to ensure all patents have appropriate follow up. Overall, the admin team have played an important part in our service development by coordinating our National MDT and by facilitating availability of all clinical information from referring clinicians in a timely fashion.

7. Mycology Reference Centre Manchester

Background to the Mycology Reference Centre

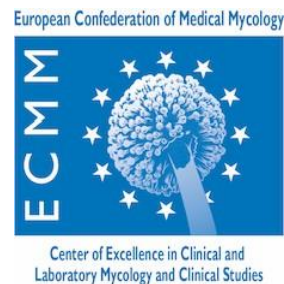
The Mycology Reference Centre Manchester (MRCM), as the only NHS Mycology Centre, offers a wide range of highly specialised mycological diagnostic services, supporting hospitals and patients throughout the UK. We also deliver services to the National Aspergillosis Centre (NAC), part of Manchester University NHS Foundation Trust (MFT), which is commissioned by NHS England. We are funded jointly by MFT, NAC and revenue from external sources.

The MRCM is a well-established and independent UKAS ISO 15189 accredited service, providing integrated conventional and molecular diagnostic testing, primarily for Manchester, north of England and Scotland but also receives daily referrals from throughout the UK and beyond. In addition, we hold a considerable research and development portfolio.

The MRCM, in partnership with the National Aspergillosis Centre, became the first clinical-diagnostic service to be recognised by the European Confederation of Medical Mycology (ECMM) as a Centre of Excellence for the diagnosis and treatment of fungal infections, achieving the top Diamond status, the first such centre in the world. Our Excellence Centre status was successfully renewed for another four years in January 2021.

The MRCM is a EUCAST Antifungal Susceptibility Testing Collaborative Laboratory and a European Fungal PCR Initiative Collaborative Centre developing international standards for various aspects of fungal diagnostics.

The MRCM also contributes to the development of UK Standards for Microbiological Investigations (SMIs) and has representation on the EUCAST Antifungal Susceptibility Testing Subcommittee, the Education Committee of the European Society for Clinical Microbiology and Infectious Diseases, the Royal College of Pathologists, the British Society for Medical Mycology and the International Society for Human and Animal Mycology. Senior members of the MRCM team have also contributed to a series of national and global guidelines (One World, One Guideline project) for the diagnosis and treatment of aspergillosis, mucormycosis, rare moulds, rare yeasts and candidiasis, as well as contributing to Health Care Infection Society and the Cystic Fibrosis Trust infection prevention guidelines.



MRCM VISION

To be a global hub for medical mycology – powered by talented people, delivering state-of-the-art clinical diagnostics, excellence in training, and world-class research and innovation

Role and Functions

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

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 be financially stable and generate income in support of MFT and reinvestment into service development
 - 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
- 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 in 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 thus empowering 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).

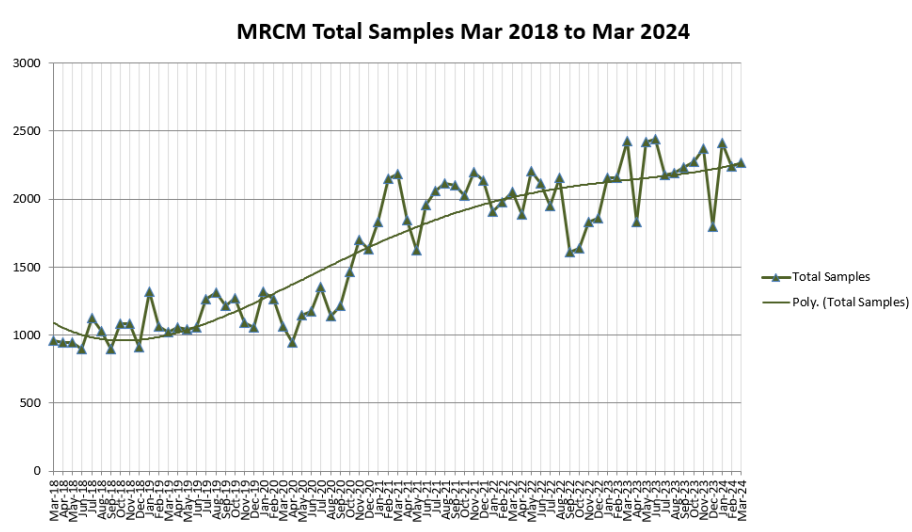
- A major innovation has been the establishment of the Mould Surveillance Service: mouldy houses, hospital environments and workplaces. This service has been particularly busy this last year.

Training, Research and Development

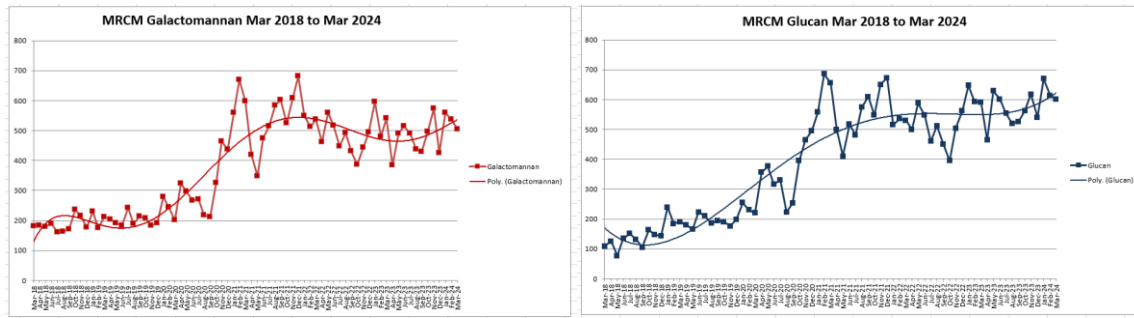
- Provision of clinical mycological training to medical and clinical scientist trainees.
- Contribution to external courses (Institute Pasteur, ESCMID, University of Manchester, University of Leeds, University of Dublin)
- Provision of undergraduate and post-graduate research training and supervision 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

Summary of 2023/24

The MRCM, in its current form, has completed its 15th year of operations. 2022/23 was another challenging yet successful year. There have been numerous developments, initiatives, and continued growth in its portfolio of tests and activities. MRCM total activity for 2023/24 was almost 27,000 specimens – an 11% increase from 2022/23.



The activity of fungal biomarkers testing, both galactomannan and glucan, remained high, with test volume of galactomannan remaining steady and glucan increasing by 9% compared with 22/23. Overall, test volume of galactomannan and glucan increased by ~131% and ~184%, respectively compared with pre-Covid-19 activity (2019/20).



Over the last five years, our activity has increased by 90% whilst our staffing by 49%.

The identification of pathogenic fungi in tissue sections is an important component of the laboratory diagnosis of fungal infections. As fungi are relatively large and morphologically distinct, it is possible to make an accurate identification of many pathogenic fungi by microscopy. The MRCM Consultant staff have increasingly been asked for second opinions on histopathological sections referred from all over the UK and beyond. In many cases, a tissue sample is submitted for pan-fungal PCR, the results from which confirm the histopathological diagnosis. Building on this experience, the team have been developing Masters level on-line modules on the morphological appearance of fungi in biopsies and post-mortem tissue.

The Mycology Reference Centre is home to the MFT Mould Surveillance Unit. The team's specialist staff provide microbial expertise, with particular emphasis on monitoring the indoor built environment for allergenic and pathogenic moulds and an integrated medical advisory expertise. Increasingly, we are assisting MFT Infection Control and Prevention teams in the investigation and remediation of hospital buildings following catastrophic flooding events and ongoing demolition and renovation works. In addition, there has been an increase in high profile cases of sudden deaths in children and adults where our scientific and medical staff have assisted Greater Manchester Police and the Coroner in investigating the possible role of allergenic and pathogenic moulds.

Key Achievements

- Successful UKAS accreditation in October 2023, with zero findings
- Continued to consistently meet all KPIs.
- Continued to deliver a centralised fungal biomarker service - galactomannan and glucan testing - within Greater Manchester, with turnaround times consistently exceeded for both tests.
- Significant input into the development and successful optimisation HIVE Beaker LIMS system to meet the needs of MRCM and users.
- Continued provision of assessments of hospital environments, workplaces and patient houses for moulds, and support for the MFT Infection Prevention and Control team as well as for other colleagues throughout the Northwest. MRCM expertise in this area is well-recognised.
- Improvement and modernisation of the laboratory infrastructure including successful implementation of MALDI-ToF, and a new extraction robot.

- A robust CPD tracker, which ensures equal CPD opportunities are offered throughout the department.
- Continued contribution to the International Fungal PCR Initiative to improve the sensitivity, specificity, and quality of fungal molecular testing, including publications.
- Continuation as a EUCAST testing laboratory for UK NEQAS for Microbiology Antifungal Susceptibility Scheme.
- Numerous clinical and laboratory audits presented at national and international meetings and written up as publications including but not limited to:
 - ECMM Candida III Study Groups. Predictors for prolonged hospital stay solely to complete intravenous antifungal treatment in patients with candidemia: Results from the ECMM candida III multinational European observation cohort study. (Published in Mycopathologica)
 - The battle against fungi lessons in antifungal stewardship from COVID 19 times (Published in International Journal of Antimicrobial Agents)
 - COVID-19 associated pulmonary aspergillosis isolates are genomically diverse but similar to each other in their responses to infection-relevant stresses. (Published in Microbiology Spectrum)
 - Development of a novel mycobiome diagnostic of fungal infection. (Published in BMC Microbiology)
 - Comparison of β -1-3-D-Glucan and Candida Mannan Biomarker Assay with Serological Tests for the Diagnosis of Candidemia. (Published in the Journal of Fungi)
 - Aneuploidy is associated with azole resistance in *Aspergillus fumigatus*. (Published in Antimicrobial Agents and Chemotherapy)
 - Knowledge and regulation on fungal contamination of sand and water: Progress report and perspectives. (Published in Medical Mycology)
 - Development of a novel mycobiome diagnostic for fungal infection. (Published in BMC Microbiology)

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.

MRCM is an ESCMID collaborative centre and hosts numerous observerships every year.

RR is a member of Royal College of Pathology Special Advisory Committee for Microbiology and Virology. She is also on the Editorial Board for the College's eLearning platform, Pathology Portal.

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 and appointed as the Lead for ESCMID Academy

Lily Novak-Frazer is the Honorary Treasurer of the British Society for Medical Mycology.

Malcolm Richardson is the President of the British Society for Medical Mycology.

Strategic Objectives for 2024/2025

- Continuing to provide an exemplary NHS reference mycology service for the UK and beyond - delivering a service, which is comprehensive, interpretative, timely, accredited and appropriate to user needs
- Maintaining international, national, and local leadership in medical mycology diagnostic services, and training
- Maintaining UKAS ISO 15189 accreditation and the European Centre of Excellence Diamond status
- Maintaining good working relationships with other departments within the Trust, and colleagues in other hospitals, universities, and institutions
- Assuring that all MFT patients have access to the same high standard mycology diagnostics in a timely manner including provision of support for the diagnosis of systemic fungal infections (aspergillosis, candidosis, mucormycosis)
- Continue to contribute to MFT guidelines involving fungal infections and monitoring and managing environmental risk factors from mould exposure
- To continue the development and implementation of the MFT infection strategy
- Maintaining an excellent and close working relationship with MFT Infectious Diseases Department, the National Aspergillosis Centre and other MFT Infection Services and developing these further
- Continue to develop our collaboration with MMMP
- To develop and validate the use of NGS as a replacement for pyrosequencing
- To develop and validate NGS for diagnosis of superficial infections
- Continue to develop our Environmental Mould Surveillance Service and supporting MFT IPC.
- To provide a supportive, caring, safe, appropriate and comfortable working environment which is inspirational and motivating that empowers the team
- Reacting to emerging fungal infections (for example, *Candida auris* in the critical care setting)
- To continue to invest in leadership to ensure a strong management team and clinical leadership
- Focus on staff development, career progression and quality CPD opportunities

- Focus on the MFT research and innovation ambitions, in partnership with the University of Manchester and the European Confederation of Medical Mycology, and by collaborating on clinical trials with Pharmaceutical companies
- To initiate the first phase to introduce next generation sequencing into our diagnostic portfolio – development ongoing, NIHR Manchester Biomedical Research Centre funded, in collaboration with the Manchester Fungal Infection Group
- To maintain our existing arrangements with the University of Manchester. Currently MRCM staff have either substantive or honorary contracts with the Manchester Fungal Infection Group, Division of Evolution, Infection and Genomics, University of Manchester (five staff members)
- Supporting Patient and Public Engagement activities delivered by the MFT Aspergillosis Communications Team
- Keeping the MRCM website (www.mrcm.org.uk) up to date and continue to be active on professional social media (LinkedIn).
- Contribute to the ongoing development of the Division of Laboratory Medicine. To ensure that the MRCM is involved at an early stage in operational and strategic service plans which is vital for patient pathway changes.

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	<ul style="list-style-type: none"> • Weekly huddles to discuss issues. • A 'catch-up' meeting six months after appraisals • Reminding staff that senior staff have a 'door always open' policy. • Staff surveys 	<ul style="list-style-type: none"> • Staff retention • Improvement in appraisal review wheel scores 	<ul style="list-style-type: none"> • Staff appraisals 	
To continue to provide training across all tests we offer.	<ul style="list-style-type: none"> • Senior staff meeting to discuss training needs. Devise a training rota and schedule in dates to commence training of staff 	<ul style="list-style-type: none"> • Staff competent in a range of tests • Granting annual leave becomes easier 	<ul style="list-style-type: none"> • Using the competency tracker 	
To expand our testing portfolio, keeping pace with new technological and treatment developments	<ul style="list-style-type: none"> • New tests and technologies discussed at Senior staff meetings 	<ul style="list-style-type: none"> • New tests and technologies available at MRCM 	<ul style="list-style-type: none"> • Senior staff meetings 	
To continue to support staff with CPD and further education	<ul style="list-style-type: none"> • Continue to attend DLM Training and Competency Group Meetings to discover new opportunities. • Continue to offer access to virtual and in person conferences and courses. • Investigate the opportunity for IBMS specialist portfolio in mycology 	<ul style="list-style-type: none"> • Staff have a variety of reflective statements in CPD portfolio 	<ul style="list-style-type: none"> • This will be monitored in the laboratory's quarterly quality reports 	<ul style="list-style-type: none"> • 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 expand drugs offered for MIC testing. This is to include Fosmanogepix, Olorafim and Rezafungin.	<ul style="list-style-type: none"> • Validation of new drugs 	<ul style="list-style-type: none"> • Implementation of new drugs 	<ul style="list-style-type: none"> • Validation meetings • Senior staff meetings 	

To continue to progress with a replacement method for Pyrosequencing.	<ul style="list-style-type: none"> Validation of new procedure 	<ul style="list-style-type: none"> Implementation of new procedure ETS application 	<ul style="list-style-type: none"> Validation meetings Senior staff meetings 	
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Quality and IT Objectives

Objective	Achieved by:	How will we know we have succeeded?	How will this be monitored?
To encourage staff to take an active role within the QMS system, to allow us to remain on track with QMS and maintain our UKAS ISO 15189 accreditation.	<ul style="list-style-type: none"> Implementing quality huddles To provide training on how to undertake quality tasks, including documentation review and completing, addressing, and closing non-conformances 	<ul style="list-style-type: none"> Documentation review percentage is $\leq 10\%$ Non-conformances are addressed and closed within the timeframe documented in MRCM-PR-QU6 	<ul style="list-style-type: none"> This will be monitored in the laboratory's quarterly quality reports and on the QMS monthly overview working spreadsheet
To improve the total (patient to patient) TAT for all MRCM tests within MFT	<ul style="list-style-type: none"> Streamlining specimen transportation Beaker/HIVE 	<ul style="list-style-type: none"> Audits 	<ul style="list-style-type: none"> Audits
To continue to engage with the HIVE EPR programme to optimise Beaker.	<ul style="list-style-type: none"> Working with the HIVE analysts to continue to develop a fit for purpose LIMS 	<ul style="list-style-type: none"> Beaker is functioning to the department's needs. 	<ul style="list-style-type: none"> This will be monitored by the laboratory's change control process
Continue to implement the new UKAS ISO 15189 2022 standard	<ul style="list-style-type: none"> Attending DLM monthly task and finish groups Attending courses and conferences regarding changes to the standard Implementing departmental UKAS standard meetings with senior staff to discuss and implement any changes 	<ul style="list-style-type: none"> Successful accreditation against the new UKAS standard 	<ul style="list-style-type: none"> Successful accreditation against the new UKAS standard

Financial Expectations for 2024/2025

- To maintain increased levels of activity and thus secure funding for additional staffing costs, particularly for clinical authorising, and consumable costs:
Due to increased clinician awareness and rapid TAT, demand for our fungal biomarker service remains high
- To seek to increase external client income, both clinical and veterinary diagnostics, and environmental services. This is dependent on increased staffing and effective marketing.
- To seek harmonisation of GP pricing tariff (via Integrated Care Boards) for superficial mycology.
- To seek funding for an IT Lead to support ongoing expectations of HIVE/Beaker upgrades
- Further external income from providing centralised diagnostic services for clinical trials of new antifungal drugs.

Anticipated cost pressures

- Continued high activity, especially fungal biomarkers service, from MFT and external sources
- Under-recovery of external income whilst P2P block payments are in place for Greater Manchester providers throughout 2024/25, and uncertainty over new financial arrangements of system funding
- Inflationary price increases on consumables, kits, and maintenance costs, up to 10% in some cases
- Expected ask for contribution to NAC Communications team or updating of website
- Higher than expected Consultant recharges
- Material costs for the NGS development work.

Deliverables for 2024/2025

Target	Milestones	Timelines	Comments
Optimisation of HIVE Beaker LIMS	Optimise software Input into BAU staff training	Ongoing	
Optimisation of Q-pulse	Seek further training to ensure all modules are being used effectively Use of asset module Use of supplier module	Ongoing	
Maintain UKAS ISO 15189 accreditation	QMS monitored via QMS monthly overview working spreadsheet	Ongoing	Full UKAS inspection expected May 2023
Implementation of the new UKAS ISO 15189 2022 standard.	Participate in the Task and Finish groups Perform Gap analysis between both standards	Ongoing Expected date of change 2025	Attend external courses and meetings to further understanding of change
Implementation of MALDI-ToF technology for mould identification	Validation of the test for mould identification	Validation by the end of 2023 Added as ETS to next UKAS assessment	
Introduction of <i>Aspergillus</i> qPCR for blood specimens	Submit new test application Validation of the assay Begin offering service	Dependent on New Test Application	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
Introduction of Evolis platform for the automation of biomarker testing	Start to develop a business case for funding Submit application for new tests Validation of platform and assays Begin offering service	By March 2024	Once funding for platform is secure, funding and application to introduce new mycology diagnostic tests can be submitted
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 Biochemistry staff availability

Other Aims for 2024/2025

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

Staffing, Quality, IT

Staffing

- Create an IT Lead role– there is a need for a permanent staff member to free clinical scientist time for laboratory and quality tasks.
- 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 Training and Competency 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.
- Complete the business case for the Environmental Mycology service to be able to respond to the increased workload from the police and the coroner.
- Funding to be confirmed for a Band 6 Biomedical Scientist post and a Band 3 Medical Laboratory Assistant post.
- Continue to utilise the CPD tracker to ensure equal opportunities across the department.

Quality

- The MRCM is preparing for the transition to the updated ISO 15189:2022 and assessment in November 2024 to maintain the current UKAS accreditation status.
- 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.
- QMS is monitored monthly via QMS monthly overview working spreadsheet. Monitoring monthly ensures that we maintain our UKAS ISO 15189 accreditation.
- 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.
- The development and implementation of DLM wide 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 and hospital newsletters.
- Continue to be involved with the optimisation and development of HIVE Beaker LIMS.
- To provide external users with electronic reports (NPEx)
- All this will require an IT trained and dedicated person: The discussion of an IT role for MRCM is currently underway. The IT role will free clinical scientist time for laboratory and quality tasks.

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 renewal of award as an ECMM Centre of Excellence in Clinical and Laboratory Mycology and Clinical Studies
- 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, including University teaching at numerous universities
- 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
- Access to the expertise of the National Aspergillosis Centre Communications team and their support with our website.
- Continuous Professional Development opportunities offered to all staff throughout the year
- The merger of WTWA Infectious Diseases service with the NMGH service has allowed a closer working relationship with all MFT ID specialists, resulting in a better patient service provided
- Expansion of training programmes for UK and overseas trainees
- HIVE electronic patient record system and Beaker LIMS for clearer and faster reporting as well as audit and demand management

Weaknesses

- Staff/workload ratio does not allow enough focus on R&I or CPD.
- Scientific and clinical staff using their time to do IT tasks and struggle to do what they should do.
- No full-specification Category III containment facility
- Limited resilience in senior staff numbers

Opportunities

- To continue 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 diagnostic platforms

Threats

- Lack of focus on R&I due to staff/workload ratio - not attractive to the highly educated and published members of staff.
- Retraction of laboratory space by University of Manchester.
- Lack of dedicated IT Lead
- Challenges in retaining highly dedicated staff with clear career progression

Future Plan and Timelines

Key Target	Comments
Introduction of new assays including: <ul style="list-style-type: none"> • <i>Aspergillus</i> IgG/IgM LFD • <i>Aspergillus</i> galactomannan LFA as POC test 	<ul style="list-style-type: none"> • This is a long-term plan over the next five years.

<ul style="list-style-type: none"> • Introduction of <i>Aspergillus</i> PCR on blood specimens • Mucorales PCR • Re-introduction of Pneumocystis PCR on saliva and respiratory specimens • PCP resistance testing • Investigate the development of an in-house <i>Aspergillus fumigatus</i> specific probe 	<ul style="list-style-type: none"> • Partial validation has been performed for some of these assays (through university projects). New test applications will be submitted.
Improve user communication and education to ensure we are meeting demand and providing a quality service	<ul style="list-style-type: none"> • Continue to engage with users via user surveys. • Continue to be involved in hospital and GP newsletters
Keeping up to date with new technologies and tests to ensure we remain at the forefront of Mycology	<ul style="list-style-type: none"> • This is a long-term plan. Implementation of new tests and technologies will be a 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Continue to engage with users via user surveys.
Retention of experienced and dedicated staff	<ul style="list-style-type: none"> • This is a rolling departmental goal. MRCM have 24 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 offer	<ul style="list-style-type: none"> • 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.

8. Statutory reports

8.1 MRSA

No cases of MRSA were reported.

8.2 *C. difficile* and CPE infections

No cases of *C. difficile* infection were reported.

No CPE (carbapenamase producer) cases were reported

8.3 Serious Untoward Incidents (SUIs)

No SUI's were reported.

8.4 Complaints

There were no formal complaints in the Year 2023-2024

8.5 High impact learning assessment (HILA)

One HILA was carried out in 23/24. A patient was started on voriconazole in June 2023. A voriconazole blood level was done at the follow up appointment and was slightly elevated at 5.89mg/L. However, the dose was not reduced as the patient did not report any side effects and it was decided to monitor the level at the subsequent clinic visit. However, the patient was subsequently admitted to hospital with weight loss and poor appetite. The voriconazole level was 8.03 mg/L, the clinical picture therefore was consistent with voriconazole toxicity. Voriconazole was stopped, the patient's symptoms improved and he was discharged. The patient was informed about this drug induced side complication and duty of candour was performed. In the HILA meeting held in November 2024, the following points were decided and were shared with the team:

- Clinical team will be reminded that if a decision is made not to alter the dose after out-of-range antifungal TDM result, or not to repeat TDM, then the reason for this should be documented on HIVE.*
- Clinical team will be reminded to ensure patients have contacted details of the NAC service when they start treatment, and to ensure NAC specialist nurses are informed when a patient starts antifungal treatment. All new patients should be given a new patient pack which is available in chest clinic.*
- The NAC antifungal TDM policy will be circulated again to all relevant colleagues to ensure they are aware of it, and to remind them it is available on the NAC shared drive.*
- Clinical team will be asked to repeat TDM for voriconazole within 2-3 weeks if the first level is >5 mg/L or < 2 mg/L, due to the non-linear pharmacokinetics of the drug.*
- An audit of actioning of antifungal drug levels will be carried out.*

9. Audit and Quality Improvement

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.

Audits in 23/24:

Quality Improvement Projects: Aspergillosis Physiotherapy

Improvement to patient journey:

Aim- improvement in patient journey through Friday/ Wed clinics, reduce unnecessary referral to physio solely to aid sputum procurement.

Method- we looked at new patient assessments and sputum sampling at initial appointments (what got sent) as usual practise. We looked at this either side of the intervention (20 patients were sent letter and pots in advance of their appointment).

Results-

Period 1 usual care (Oct 2023) – n=10 patients, total samples sent 17 (3 patients-zero, 2 patients 4 samples (seen by physio), 4 patients 2 samples, 1 patient 1 sample)

Intervention – n=20 patients, total samples sent 48 3 patients 5 samples, 2 patients 4 samples, 3 patients 3 samples, 5 patients 2 samples, 4 patients 1 sample and 2 patients zero samples (one not productive unless exacerbating, one DNA/admitted acutely)

Period 2 usual care June 2024- n=10 patients, total samples sent 5 (7 patients zero samples, 2 patients 2 samples, 1 patient 1 samples)

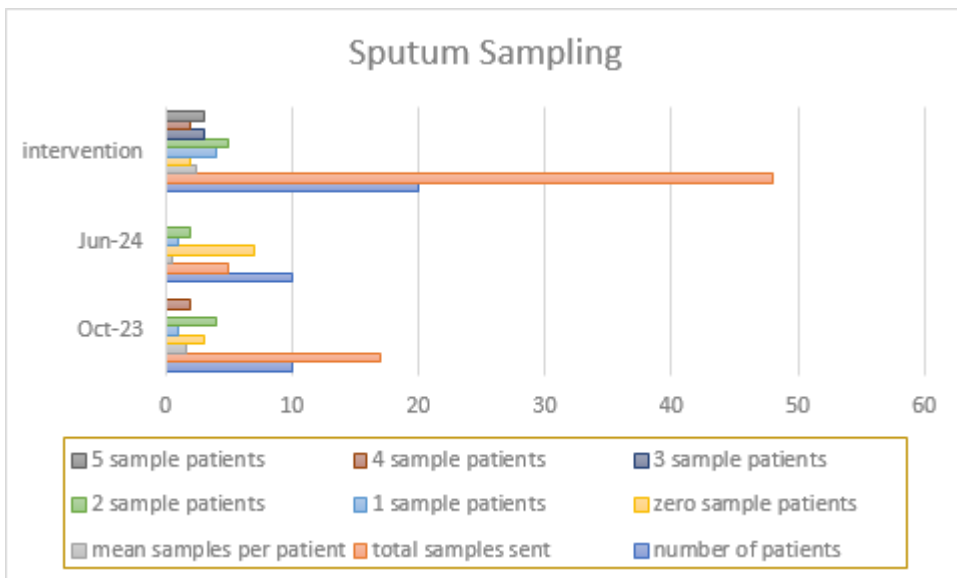
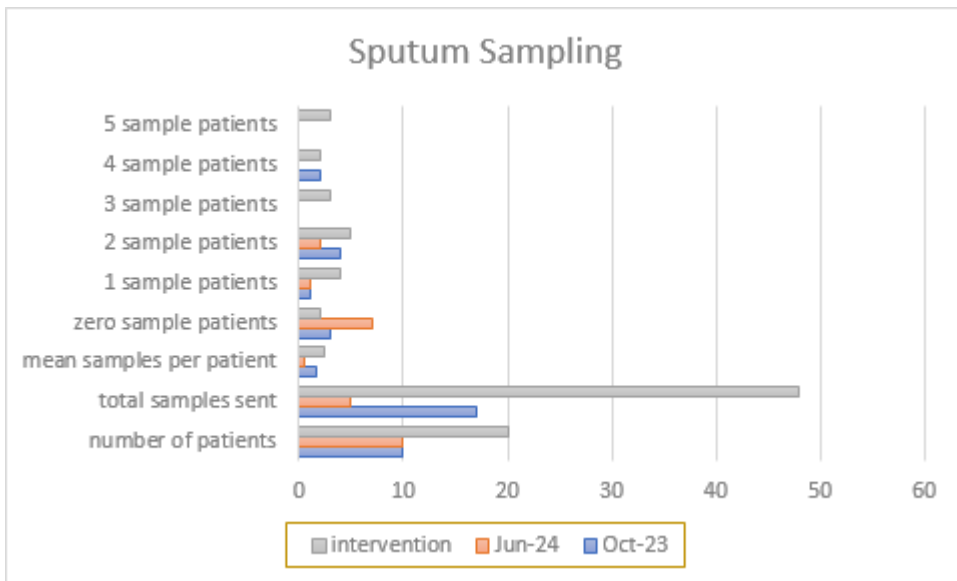
Period	number of patients	total samples sent	mean samples per patient	zero sample patients	1 sample patients	2 sample patients	3 sample patients	4 sample patients	5 sample patients
Oct-23	10	17	1.7	3	1	4	0	2	0
Jun-24	10	5	0.5	7	1	2	0	0	0
intervention	20	48	2.4	2	4	5	3	2	3

Analysis

Many patients were able to bring samples to their initial clinic appointments. This has potential to improve patient journey through the clinics

Actions

We fed back the results and hope that with adequate administrative support we will be able to make this practise usual patient care.



Physiotherapy referrals:

Background

We examined patterns of referrals to physio from Wed and Fri clinics to identify patterns and potential areas to improve.

Methods

We reviewed 130 clinic appointments Sept/Oct 2022 and 170 patient visits Sept 2023 assessing the following dimensions to scope the potential for physio support:

- Any record of seeing resp physio today/ prev
- Appropriate for physio (based on **that day's** clinical assessment documentation)
- Principal reason appropriate for physio

- New or F/U
- Telephone/Video/FTF appointment

A tandem evaluation of referrals July 2023-June 2024 examined referrals by clinician group, referral methods and ensuing physio follow up.

Key findings:

From the 2023 data:

- Although 112 weren't appropriate for physio on the day, 57/112 had evidence of previous outpatient respiratory physio
- 36 (21%) no previous /same day physio but appropriate (8FTF, 8 Vid, 19 Tel)
 - 25 bothersome cough, 11 breathlessness
 - 22 appropriate for physio that day and had prev/ that day input (1 Vid, 12 Tel, 9FTF)

	2022 data n=130	2023 data n=170
Tel	71 (55%)	98 (58%)
FTF	43 (33%)	FTF 45 (26%)
Vid	16 (12%)	Vid 27 (16%)
New	13	4
Follow up	117	166
Seen physio today/prev?	Y 51 (39%) N 79	Y 80 (47%) N 90
Appropriate for physio?	Y 57 (43%) N 73 (57%)	Y 58 (34%) N 112 (66%)
Bothersome cough/ mucus plugging	42	43
Worsening breathlessness	10	13
Other	5	23
Not indicated	73	112

Analysis of 171 new referrals to physiotherapy 1/7/2023/30/6/2024

Consultants	63 (range 2-20, mode 5, mean 7.9)
Nurses	29 (range 4-17, mean 9.7)
Fellows	33 (mean 6.6)
Other	46

- Referral to treatment times: range 0-134 days (zero=70, 14 within 2 weeks)
- Referral methods
 - Email (6); Face to face (95); HIVE InBasket (25); HIVE Secure Chat (12); MDT (10); physio triage (9)
- Physio follow up – approx. 50% of those referred and seen get followed up, 50% not required

Analysis:

Many of our patients have problems respiratory physiotherapy input could help with and indeed many have accessed this support. However there are still a significant portion of our clinic caseload who do not access/get offered this support based on the written evidence in the clinical records available.

Over the last 3 years physio new referrals have gone from 141 to 133 to 171 per annum. Although the referral increase is encouraging there is room for improvement. In 2021-2022 36 patients did not require further physio follow up (25%) compared to the 50% reported this year. This reflects a change in service provision- patients can now initiate their own physiotherapy follow up using the myMFT app if they have the technical understanding/ability.

The biggest opportunity to improve referrals seems to be to focus on the clinical fellow team members and to consider our remote consultations, especially telephone reviews.

Actions:

We have fed back our findings to the wider team and will continue to evaluate referral patterns/ clinic activity. We have ongoing strategy meetings to discuss equity of service provision. We will continue to promote our role within the team.

Audit of appropriate prescribing of co-medications in patients on antifungal medication.

Background: Antifungal drug interactions are multiple and potentially toxic. We looked for inappropriately prescribed comedications in all CPA patients and changed to a compatible combination when possible

Methods:

- Retrospective review of patient charts
- CPA clinic patient list as per 24/01/2024
- Review between January and October 2024

- Information on:
 - Baseline characteristics
 - Hive medication review
 - Medication mentioned in clinic letter, comparison to previous letter
 - Potentially interacting co-medication
- Interactions according to BNF and antimicrobial pharmacists
- Itraconazole used as template azole for interaction checks
- Questionnaire
- Standards?
- Data analysis using Microsoft Excel and IBM SPSS
- Data presented as median (quartiles) and proportions (%)

Results: 316 patients included

94% had comorbidities likely requiring comedication

63% were on antifungals

Interacting medications are shown below:

Medication	Total population (n = 306)	Patients on antifungals (n = 118)	Patients not on antifungals (n = 188)
Fluticasone	57/306 (19%)	19/118 (16%)	38/188 (20%)
Beclometasone	107/306 (35%)	41/118 (35%)	66/188 (35%)
Budesonide	12/306 (4%)	3/118 (3%)	9/188 (5%)
Ciclesonide	2/306 (1%)	1/118 (1%)	1/188 (1%)
Mometasone	7/306 (2%)	2/118 (2%)	5/188 (3%)
Rifampicin	2/306 (1%)	0/118 (0%)	2/188 (1%)
Prednisone	1/306 (0.3%)	0/118 (0%)	1/188 (1%)
Prednisolone	46/306 (15%)	19/118 (16%)	27/188 (14%)
Hydrocortisone	16/306 (5%)	8/118 (7%)	8/188 (4%)
Simvastatin	2/306 (1%)	0/118 (0%)	2/188 (1%)
Atorvastatin	30/306 (10%)	5/118 (4%)	25/188 (13%)
Rosuvastatin	14/306 (5%)	9/118 (8%)	5/188 (3%)
Pravastatin	21/306 (7%)	6/118 (5%)	15/188 (8%)
Warfarin	7/306 (2%)	1/118 (1%)	6/188 (3%)
Edoxaban	11/306 (4%)	4/118 (3%)	7/188 (4%)
Apixaban	13/306 (4%)	2/118 (2%)	11/188 (6%)
Rivaroxaban	4/306 (1%)	0/118 (0%)	4/188 (2%)
Dabigatran	2/306 (1%)	1/118 (1%)	1/188 (1%)
Enoxaparin	1/306 (0.3%)	1/118 (1%)	0/188 (0%)
Pantoprazole	7/306 (2%)	1/118 (1%)	6/188 (3%)
Lansoprazole	51/306 (17%)	18/118 (15%)	33/188 (18%)
Omeprazole	62/306 (20%)	28/118 (24%)	34/188 (18%)
Esomeprazole	3/306 (1%)	0/118 (0%)	3/188 (2%)
Famotidine	7/306 (2%)	0/118 (0%)	7/188 (4%)
Alginates etc.	7/306 (2%)	1/118 (1%)	6/188 (3%)

Medication	Total population (n = 306)	Patients on antifungals (n = 118)	Patients not on antifungals (n = 188)
Fentanyl	3/306 (1%)	0/118 (0%)	3/188 (2%)
Methadone	2/306 (1%)	1/118 (1%)	1/188 (1%)
Buprenorphine	2/306 (1%)	2/118 (2%)	0/188 (0%)
Oxycodone	5/306 (2%)	1/118 (1%)	4/188 (2%)
Digoxin	6/306 (2%)	0/118 (0%)	6/188 (3%)
Amlodipine	21/306 (7%)	7/118 (6%)	14/188 (7%)
Lercanidipine	2/306 (1%)	0/118 (0%)	2/188 (1%)
Nifedipine	4/306 (1%)	1/118 (1%)	3/188 (2%)
Diltiazem	2/306 (1%)	1/118 (1%)	1/188 (1%)
Eplerenone	2/306 (1%)	1/118 (1%)	1/188 (1%)
Ranolazine	3/306 (1%)	1/118 (1%)	2/188 (1%)
Sildenafil	9/306 (3%)	3/118 (3%)	6/188 (3%)
Mirtazapine	15/306 (5%)	8/118 (7%)	7/188 (4%)
Modafinil	2/306 (1%)	0/118 (0%)	2/188 (1%)
Quetiapine	1/306 (0.3%)	0/118 (0%)	1/188 (1%)
Sertraline	0/306 (0%)	0/118 (0%)	0/188 (0%)
Venlafaxine	7/306 (2%)	4/118 (3%)	3/188 (2%)
Zopiclone	5/306 (2%)	2/118 (2%)	3/188 (2%)
Mirabegron	3/306 (1%)	1/118 (1%)	2/188 (1%)
Solifenacin	3/306 (1%)	1/118 (1%)	2/188 (1%)
Tamsulosin	13/306 (4%)	4/118 (3%)	9/188 (5%)

Conclusions: 84 moderate and 5 severe drug drug interactions were identified. All severe interactions were addressed. A new policy on azole-inhaled steroid interaction was generated. Drug interaction charts are available for clinical staff in shared folder and in induction document.

10. Research and Publications

We were awarded a grant of £251,000 by the NIHR Research for Patient Benefit scheme to conduct a randomised controlled trial of immunotherapy in CPA. The study started recruiting in June 2024. The study is sponsored by Manchester University NHS Foundation Trust. In addition, our Trust is the primary site to be selected for a clinical trial of rezafungin, a novel once-a-week antifungal agent for CPA.

This year, NAC and MRCM staff published 20 papers relating to fungi in scientific journals and shared their data with clinicians at a variety of international conferences (Full list of publications in Appendix 3).

CPA research

[Management and prognosis for *Aspergillus* nodules \(Kosmidis *et al*, 2024\)](#)

- This uncommon form of aspergillosis is particularly challenging as nodules may initially be misdiagnosed as lung cancer and have highly variable outcomes. This is distressing for patients, and can cause confusion among clinicians about whether antifungals are required and how often to do repeat chest CT scans
- Clinical characteristics and outcomes were described for a series of 23 relevant patients who were identified in the NAC database. We hope this information will help doctors to decide whether antifungal therapy is necessary, to select an appropriate monitoring schedule, and to provide patients with better information about their likely prognosis
- This work was discussed with great interest by patients in our monthly support group, several of whom have stable nodules alongside their main diagnosis of CPA. They requested that we adapt it into an online factsheet that is available here: <https://aspergillosis.org/aspergillus-nodules/>

Which factors predict mortality and treatment response in CPA? (Kosmidis *et al*, 2024)

- CPA patients are often anxious to know how likely they are to respond to antifungal treatment and how long they can expect to survive. Sadly, it is difficult to give a satisfactory answer because CPA is an extremely variable disease and there is very little data in the literature.
- This study compared the outcomes of 59 CPA patients against their baseline characteristics (symptoms, blood tests, CT scan results) and how well they responded to antifungal treatment
- Mortality was higher among patients with raised *Aspergillus* IgG and inflammatory markers, but lower among people who responded well to antifungals. It did not seem to correlate with underlying conditions such as COPD

Does mould exposure worsen COPD symptoms? (Kosmidis *et al*, 2023)

- Questionnaires were completed by 140 COPD patients at MFT (with or without CPA), in order to estimate their level of exposure to mould spores and determine whether this correlated with their COPD symptoms.
- Patients who vacuum at least once per week and who ask guests to remove their shoes when visiting tended to have fewer GP visits and courses of antibiotics. However, an association was not seen between symptoms and home dampness, pet ownership or presence of carpets. This was of great interest to our patient group, who are highly motivated to find ways of keeping well

CPA guides for generalist clinicians

NAC staff also used their expertise to contribute to several useful review articles to help disseminate up-to-date information about CPA among the wider medical community

- **Armstrong-James et al (2023)** Dr Kosmidis co-authored a review of current CPA management options and the development pipeline for new antifungals and immunotherapy
- **Carter et al (2024)** Dr Baxter co-authored a review of CPA aimed at general physicians, which explains the roles of all the different members of the MDT
- **Evans et al (2024)** Dr Lawal and Dr Kosmidis co-authored an overview of CPA for the journal *Seminars in Respiratory & Critical Care Medicine*

MRCM & diagnostics

- ***Aspergillus* sensitisation in asthma (Wang et al, 2023)** A lateral flow test is available for *Aspergillus* IgG-IgM antibody levels. Its accuracy was tested using blood samples from 65 patients at MFT with moderate-severe asthma, including some who also had ABPA or SAFS. Results show it is potentially useful for ruling out ABPA, especially for asthma clinics in countries with limited access to a mycology reference laboratory
- **Azole resistance via aneuploidy (Khateb et al, 2023)** Professor Richardson collaborated with researchers at the University of Manchester to look for the underlying genetic mechanism of azole resistance among clinical isolates of *Aspergillus*. They found aneuploidy (duplication of whole sections of chromosome) in several CPA isolates taken from NAC patients, but not in strains isolated from invasive aspergillosis patients or from the environment. This had never been seen in *Aspergillus*, and this will help guide care of CPA patients on long-term azoles
- **New *Tef1* sequencing assay (Weaver et al, 2024)** MRCM staff developed a new DNA sequencing test based on a single-copy fungal gene (*Tef1*) that overcomes several technical difficulties associated with more commonly-used multicopy genes (e.g. ITS). This could in future be used to identify species in clinical samples containing mixtures of moulds and/or yeasts
- **Fungal contamination of beaches (Gangneux et al, 2024)** Professor Richardson is part of the ECMM/ISHAM MYCOSANDS study group, which produced this review of fungal contamination of beaches and recreational water. They defined a 'normal' level of fungi that has been incorporated into quality criteria in Portugal and informed WHO guidelines on recreational water

COVID-associated pulmonary aspergillosis (CAPA)

NAC and MRCM expertise has been very useful since the start of the pandemic because COVID-19 patients are at increased risk of invasive fungal infections including aspergillosis, but there was initially much confusion about the best diagnostic strategies. We are helping to ensure the right patients receive systemic antifungals while avoiding over-prescribing that can lead to resistance

- **Antifungal stewardship (Kanj et al, 2023)** Dr Rautemaa-Richardson co-authored a review describing how antifungal stewardship was applied during the pandemic for invasive fungal infections caused by *Aspergillus*, *Candida* and *Mucormycosis*
- **CAPA review (Kosmidis & Hoenigl, 2023)** A concise review of the risk factors, prevalence and mortality rates of CAPA, as well as the practical challenges in obtaining evidence

International collaborations

NAC staff also co-authored several articles with overseas clinicians who have previously worked at NAC and returned to their home countries including Ghana and Indonesia

- **Histopathology (Ocansey et al, 2024)** Dr Kosmidis co-authored a retrospective study describing mycological histopathology findings spanning 10 years in Ghana. It highlighted the need for better access to more fungal tests including culture, serology and molecular
- **Galactomannan lateral flow (Ocansey et al, 2023)** A pilot study was carried out in Ghana to see whether a lateral flow test for galactomannan (*Aspergillus* antigen) would be useful for screening haematological cancer patients for invasive aspergillosis
- **Lung mycobiome (Rozaliyani et al, 2023)** Dr Kosmidis and colleagues in Indonesia co-authored a review article about how imbalances in the lung mycobiome (the fungal ecosystem living inside the lungs) are linked with various respiratory diseases, as well as how they interact with common bacteria. This is a very neglected topic that is beginning to gain interest

Other moulds & yeasts

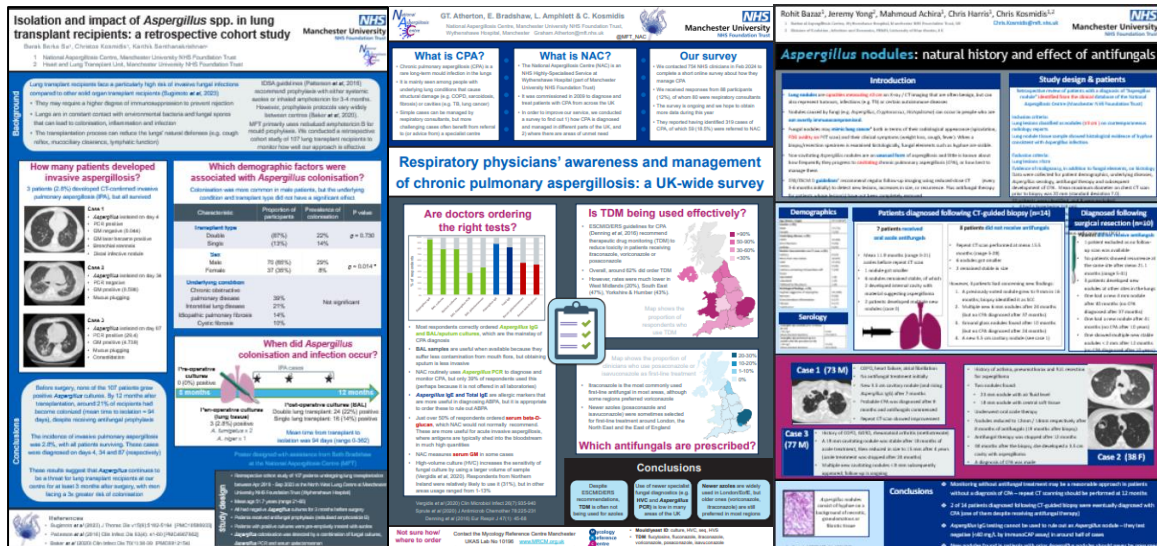
MRCM staff are also involved in research into other fungal pathogens such as *Candida* yeast, which affect many patients in NHS critical care units and haematology wards

- **Biomarkers (Eades et al, 2023)** NAC and MRCM staff led a study comparing beta-D-glucan and *Candida* mannan biomarker (antigen) tests with serological (antibody) tests for detecting life-threatening *Candida* bloodstream infections
- **Invasive *Candida*** Dr Rautemaa-Richardson co-authored several papers on data generated by the large international ECOMM *Candida* III study. These investigated whether guideline adherence affected mortality rates (Hoenigl et al, 2023), epidemiological patterns (Arendrup et al, 2023) and which factors can predict long hospital stays for patients on intravenous antifungals (Egger et al, 2023)
- **Anticytokine antibodies (Arts et al, 2024)** Dr Janssen co-authored a review article about anticytokine antibodies, which can deplete immune signalling molecules (e.g. IL-6). People who produce these antibodies may be more susceptible to infections including *Candida*, *Cryptococcus*, *Histoplasma* and *Talaromyces*

Conference presentations

Conference talks and posters are an important platform for NAC/MRCM to communicate with other clinicians and researchers, in a setting that is more interactive than journal articles.

The CARES team helps to prepare many of the conference abstracts/posters, which saves time for clinical staff and ensures that NHS branding is applied consistently.



11. Patient and public engagement

The NAC CARES (Community, Awareness, Research, Education, Support) team consisted of four members of staff: Graham Atherton (Team Lead), Lauren Amphlett (Patient communities, social media), Chris Harris (NAC Manager, phone support, retired June 2024) and Beth Bradshaw (Medical writer, Mycology).

The patients survey 2024 shows that how we are engaging patients and carers is continuing to evolve. Clinics are now seeing 41% of patients face to face (F2F) but access via phone (47%) and video (13%) remains popular. Patient preferences expressed in the survey indicate that each have very similar popularity as a choice to be seen by the medical team with video becoming more popular since 2023.

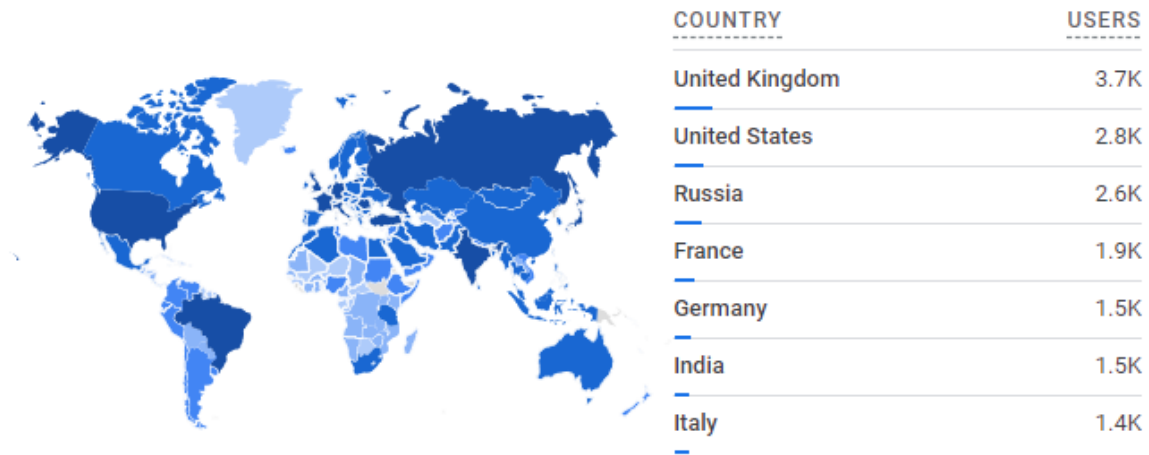
We continue to offer a range of online services and resources, with weekly social support meetings now having become a permanent fixture after being introduced during the COVID pandemic.

All patients receive text messages after every clinic visit (96% of patients can receive a text message) which seems to most efficient way to raise awareness of what we offer. We also add this information into a printed booklet designed to be given to all patients at clinic. NB we are aware that there are likely to be a small number of patients who neither receive text messages or a printed booklet but they will be informed by the newly developed footer message that goes out in paper form to every patient or patients GP/hospital after a clinic meeting.

These approaches to ensuring that all patients know of the support services and resources offered by CARES has led to increases in use of all services over the last year compared with the previous year:

- Visitors to aspergillosis.org are up 4% (5700 users per month)
- 19% have attended a patients meeting
- 42% are members of the Facebook support group (up 21%)
- 35% are aware of our weekly social support meetings (up 7%)

Users ▾ by Country



[View countries →](#)

Map shows the numbers of people accessing aspergillosis.org over the last month (July 2024). The website is available in multiple languages. People from 191 countries have visited since July 2023.

11.1 Patient Support Services

Telegram

Telegram.com is a private and confidential NHS-approved individual/group communication App. There are three groups covering CPA/ABPA/General discussion populated by a total of 88 patients (July 2024 – some patients are part of more than one group) that are almost all NAC & NHS patients. We use Telegram to answer private & confidential questions.

Monthly NAC Teams meetings

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 patients have asked for.

We record the content and publish links on <https://aspergillosis.org> to allow patients to watch at a later date. From July 2023 up to July 2024 these videos had 18000 views, 1100 hrs watch time, 212 subscribers.

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 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 on concerns such as adrenal sensitivity, claiming disability benefits & minimising their risk of exposure to antifungal-resistant spores.
- Monthly meetings provide a platform for NAC staff to give talks on a wider variety of subjects aimed at helping the ‘whole person’ including (given at an understandable level):
 - Living with COVID
 - Why do some people get aspergillosis?
 - Use of stem cells & DNA editing to repair lung tissue
 - Current clinical trials on aspergillosis both here at NAC and elsewhere
 - What biologic drugs are and how do they work for asthma
 - What is the Mediterranean diet?
 - How we manage adrenal insufficiency in patients on long term corticosteroids
 - Speech and Language Therapy
 - Managing exposure to antifungal drug resistant spores
 - Antifungal interactions
 - Food allergy and food intolerances
 - Cost control of new drugs
 - Humidity and mould in our homes
- Aspergillosis.org often hosts articles that have resulted from a Teams meeting discussion to provide detailed advice and guidance from reputable resources – this supports our talks and offers the information to a wider audience.

11.2 Professional outreach

The patient’s newsletter now has 6234 contacts, of which 100% open the newsletter at least once in the year and 37-39% open it in any month.

We have proactively reached out to clinical colleagues around the UK through a variety of channels, both to raise awareness of our services/resources and to promote best practice. In particular, we have encouraged doctors to pass on details of our support groups to any CPA or ABPA patients who would benefit from them.

December saw us talk to employees of a pharmaceutical company about our work with patients, and to give them some insight into the symptoms and life experience of people living with aspergillosis. We were told that this had a great impact.

Respiratory Futures

This year NAC was featured in the online magazine Respiratory Futures, which is produced by BTS for respiratory clinicians in the UK. This helped us promote the service and encourage people to respond to the CPA survey.

www.respiratoryfutures.org.uk/features/how-does-the-national-aspergilliosis-centre-support-treatment-of-this-rare-disease-across-the-whole-uk

Manchester GP newsletter

We wrote an item about aspergilliosis for the NHS Greater Manchester Integrated Care Board newsletter, which is distributed to all GPs across Greater Manchester. It included links to our support groups and MIMS course, as well as reminders about TDM and offering smoking cessation.

Clinician mailing list

This year we started producing a quarterly email newsletter aimed at clinicians, to keep them updated with NAC's activities and with new aspergilliosis-related publications, guidelines and events. Our clinician mailing list is mainly made up of NHS respiratory consultants who have previously interacted with NAC (referrals or MDT cases). The first issue was sent out to 50 clinicians and was opened by 98%.



News from the National Aspergilliosis Centre

Welcome to the first NAC clinician newsletter! We will send you quarterly updates with information and practical tips, so that you can make the best use of our services and help your aspergilliosis patients stay well

We will also keep you updated about our research projects and updates to the tests being offered by our partner lab (Mycology Reference Centre Manchester), as well as activities we have planned for #WorldAspergilliosisDay (Feb 3rd 2025). We may also mention important new guidelines, treatments, CPD activities and conferences that are relevant to aspergilliosis

Get in touch with Beth (Elizabeth.bradshaw2@mft.nhs.uk) if there are any topics you would like to request, or if you have any events/publications/trials you would like us to promote. We hope to nucleate a community of people with an interest in this disease so we've set up a group on NHS Networks that you can join here: www.networks.nhs.uk/groups/chronic-aspergilliosis-group

N.B. We also have another email newsletter that is aimed at patients, which is more focused on advice for keeping well and awareness activities. You are of course welcome to receive both - you can sign up via Aspergilliosis.org

[NAC's remote MDT](#) [INCAS trial \(IFNy\)](#) [BTS summer meeting](#)

[New ABPA guidelines](#) [Lung transplant prophylaxis](#) [Respiratory Futures](#)



Would you like to dial into our remote MDT?

Our aspergilliosis MDT is held weekly (Thurs 9:00-11:00) and accepts external cases via Microsoft Teams.

Why?

- Decide whether a patient needs to be referred to NAC, or can be managed locally with occasional advice from us
- Discuss whether and when to start/stop antifungals, and what options exist for patients with resistance or tolerability issues
- Discuss which tests are need to determine whether a complex patient's current ill health is likely to be caused by their aspergilliosis or one of their comorbid conditions

How?

- Only CPA (or possible CPA) cases will be accepted
- Please contact jdandnacadmin@mft.nhs.uk to be added to the list and receive a link to join the Teams meeting, or phone 01612912891 to discuss
- You will need to complete a [pro forma](#) with an outline of the case
- Please request for imaging to be transferred via your local PACS team several days in advance (the transfer can take 24-48 to go through)
- We can email the MDT outcome to you after the meeting



Now recruiting: INCAS Adjunctive IFN γ for CPA

We have just opened recruitment for the INCAS trial (Phase2 open-label RCT [NCT05653193](https://www.clinicaltrials.gov/ct2/show/study/NCT05653193))

We previously found that many CPA patients produce reduced amounts of IFN γ ([Colombo et al. 2022](#)) and that prescribing it may help reduce the frequency of exacerbations and hospitalisation ([Monk et al. 2020](#)).

However, more evidence is needed before this treatment can be recommended more widely. We are looking to recruit 50 CPA patients over 2 years for a NIHR-funded feasibility study, which if successful will lead into a larger-scale trial.

Trial design:

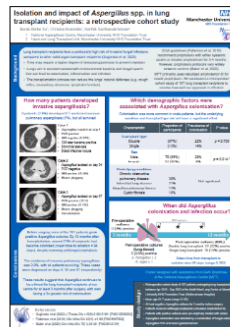
- Azole treatment (n=25) vs. azole treatment + IFN γ (n=25)
- IFN γ -1B (0.1mg/0.5ml injection)
- Self-injected 3 x weekly for 3 months
- [Read the full inclusion/exclusion criteria](#)
- Measuring: cavity size (chest CT); QoL score

If you have any patients who may be suitable, please get in touch with [Dr Chris Kosmidis](#) before approaching them. We will reimburse participants for travel costs, and will provide support them with managing side effects and the self-injection process. **N.B. the trial medicine must be given within 8 weeks of starting antifungals.**



How long should lung transplant recipients use mould prophylaxis?

NAC staff helped collect data on *Aspergillus* risks among MFT patients, presented at Fungal Update



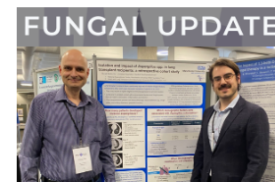
Lung transplant recipients are at particular risk of *Aspergillus* colonisation and infection as the lungs are in constant contact with fungal spores and bacteria from the environment.

They also tend to need higher levels of immunosuppression to prevent rejection.

IDSAs recommend 3-4 months of antifungal prophylaxis but the side effects can be difficult to tolerate

Our doctors presented data collected at MFT as a poster at Fungal Update (Mycology2024) in London

Of 107 lung transplant recipients, there were 3 cases of invasive pulmonary aspergillosis (all survived).



British Thoracic Society stall

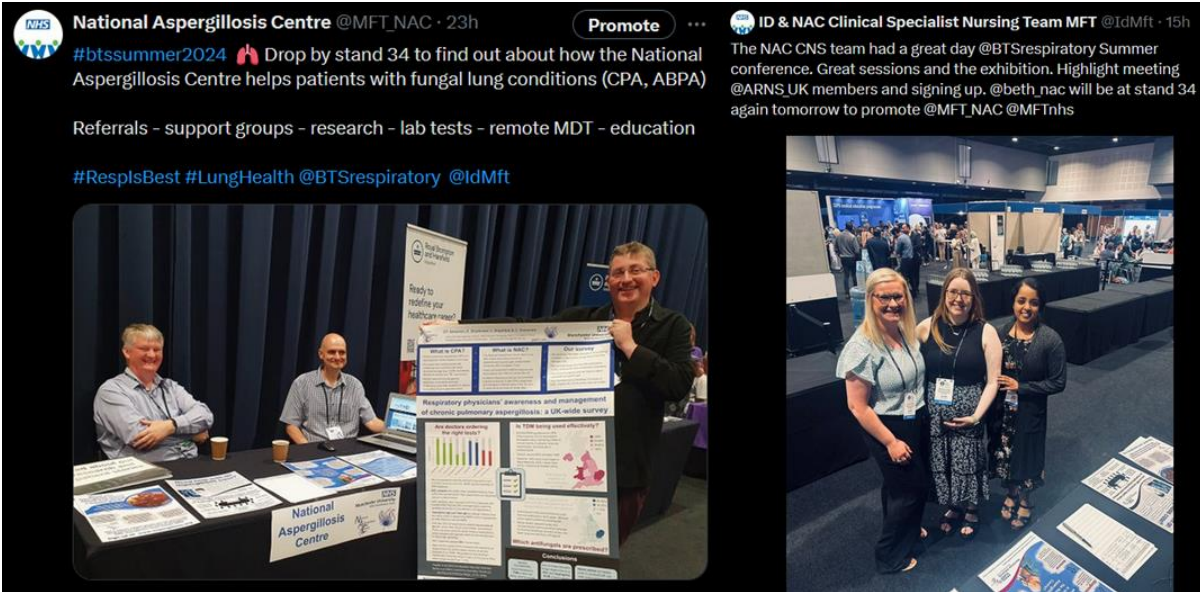
This year, we presented our first exhibition stand at the summer meeting of the British Thoracic Society (BTS) in Manchester, to promote our services and research among respiratory clinicians. While most consultants were aware that NAC accepts referrals for aspergillosis patients, a large proportion did not know we also offer patient support groups, laboratory testing and a remote MDT.

Many visitors took a digital copy of the support group poster and since then we have seen a steady increase in the rate of requests to join our Facebook group

18 clinicians requested further information and joined our mailing list

Many consultants were pleasantly surprised to learn that we offer a remote MDT, so a quick guide for external presenters was included in the clinician newsletter

Having a physical space for delegates to chat informally with NAC staff and browse printed materials was very helpful. It allowed us to open up conversations with clinicians that we had not been reaching – many had assumed that NAC ‘wasn’t relevant to them’ because they only came across 1-2 aspergillosis cases per year. This revealed a potentially large group of doctors who are under-utilising our services, which we can target during future promotion activities.



Posters designed to promote NAC services at BTS 2024

Treatment

Treatment plan will be tailored to each patient's needs and comorbid conditions, but can include these:

- Antifungals & antifungal TDM
- Home delivery of medication
- Postal packs for sputum samples
- OPAT (if in area)
- BAE (if in area)

Support

- Online patient support groups (Facebook, Zoom,)
- Patient information website (Aspergillosis.org)
- Direct phone number to talk with specialist nurses
- Specialist pharmacists to help manage side effects and drug interactions
- Specialist physiotherapists to teach breathing techniques and using nebulisers

What happens when a patient is referred to the National Aspergillosis Centre?

Diagnosis

- Lung function
- Chest CT
- Serology (IgG, IgE)
- Susceptibility testing
- Further immunology if appropriate

Referral

Consultants can make a direct referral for possible CPA patients with positive Aspergillus cultures or serology, plus scans showing a lung cavity present for >3 months

Consultants or GPs can refer non-CPA cases via NHS e-Referral

Discharge

Once the patient is stable, they are discharged back to their GP or consultant with a long-term care plan. They can be re-referred if their situation changes

Manchester University NHS Foundation Trust

Find out more about us and make a referral on the MFT website:
<https://mft.nhs.uk/wythenshawe/services/infectious-diseases/national-aspergillosis-centre/>

Would your aspergillosis patient benefit from joining a support group?

Many patients with rare diseases feel socially isolated and struggle with the day-to-day management of their condition

Fatigue Pain Uncertainty Side effects Depression

Twice-weekly social chat on Teams where patients can support each other emotionally and talk with other people who really get it

Monthly Teams meeting with presentations by the CARES team on requested topics including nutrition, mental wellbeing, breathlessness, winter viruses, participating in clinical trials

Private Facebook group for sharing tips and experiences, closely moderated by NHS staff to prevent misinformation

NAC's patient support groups are free and accept all UK patients with chronic forms of aspergillosis (CPA, aspergilloma, fungal nodules, ABPA)

Sign up at www.aspergillosis.org

Order specialist fungal diagnostics from the Mycology Reference Centre Manchester

Diagnostics • Environmental • Research • Training



Identification
 High-volume culture
 Monitoring of indoor environments
 Susceptibility
 PCR
 TDM
 Galactomannan
 Beta-D-glucan
 Histology slide review
 Pyrosequencing
 Cryptococcal antigen
 High vaginal swab

Send us a sample



NHS Mycology Reference Centre Manchester
 Manchester University NHS Foundation Trust
 UKAS lab no. 10196

Prices, TATs & referral form:
<https://mrcm.org.uk>

Need help with an aspergillosis case?

Do I need to order TDM?
 She just isn't getting better...is this strain azole resistant?
 Is this going to progress into something worse?
 Is this CPA or just COPD with a lot of chest infections?
 Should I prescribe voriconazole or posaconazole?

NHS Manchester University NHS Foundation Trust
 National Aspergillosis Centre

Join our MDT remotely for expert advice on *Aspergillus* diagnostics and treatment

Consultants with years of aspergillosis experience
 Specialist physiotherapists
 Specialist nurses
 Antifungal pharmacists
 Admin team

On-site mycology reference laboratory
 Radiologists for diagnosis and BAE
 CARES team provides reliable patient information and runs support groups

<https://mft.nhs.uk/wythenshawe/services/infectious-diseases/national-aspergillosis-centre/>

CPA survey poster



GT. Atherton, E. Bradshaw, L. Amphlett & C. Kosmidis

National Aspergillus Centre, Manchester University NHS Foundation Trust,
Wythenshawe Hospital, Manchester Graham.Atherton@mft.nhs.uk

@MFT_NAC



What is CPA?

- Chronic pulmonary aspergillosis (CPA) is a rare long-term mould infection in the lungs
- It is mainly seen among people with underlying lung conditions that cause structural damage (e.g. COPD, sarcoidosis, fibrosis) or cavities (e.g. TB, lung cancer)
- Simple cases can be managed by respiratory consultants, but more challenging cases often benefit from referral to (or advice from) a specialist centre

What is NAC?

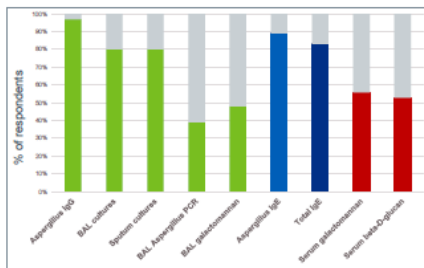
- The National Aspergillus Centre (NAC) is an NHS Highly-Specialised Service at Wythenshawe Hospital (part of Manchester University NHS Foundation Trust)
- It was commissioned in 2009 to diagnose and treat patients with CPA from across the UK
- In order to improve our service, we conducted a survey to find out 1) how CPA is diagnosed and managed in different parts of the UK, and 2) where there are areas of unmet need

Our survey

- We contacted 754 NHS clinicians in Feb 2024 to complete a short online survey about how they manage CPA
- We received responses from 88 participants (12%), of whom 80 were respiratory consultants
- The survey is ongoing and we hope to obtain more data during this year
- They reported having identified 319 cases of CPA, of which 59 (18.5%) were referred to NAC

Respiratory physicians' awareness and management of chronic pulmonary aspergillosis: a UK-wide survey

Are doctors ordering the right tests?

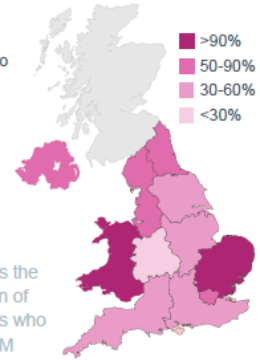


- Most respondents correctly ordered **Aspergillus IgG** and **BAL/sputum cultures**, which are the mainstay of CPA diagnosis
- BAL samples are useful when available because they suffer less contamination from mouth flora, but obtaining sputum is less invasive
- NAC routinely uses **Aspergillus PCR** to diagnose and monitor CPA, but only 39% of respondents used this (perhaps because it is not offered in all laboratories)
- Aspergillus IgE** and **Total IgE** are allergic markers that are more useful in diagnosing ABPA, but it is appropriate to order these to rule out ABPA
- Just over 50% of respondents ordered **serum beta-D-glucan**, which NAC would not normally recommend. These are more useful for acute invasive aspergillosis, where antigens are typically shed into the bloodstream in much high quantities
- NAC measures **serum GM** in some cases
- High-volume culture (HVC) increases the sensitivity of fungal culture by using a larger volume of sample (Vergidis *et al*, 2020). Respondents from Northern Ireland were relatively likely to use it (31%), but in other areas usage ranged from 1-13%

Vergidis *et al* (2020) Clin Microbiol Infect 26(7):935-940
Sprute *et al* (2020) J Antimicrob Chemother 78:225-231
Denning *et al* (2016) Eur Respir J 47(1): 45-68

Is TDM being used effectively?

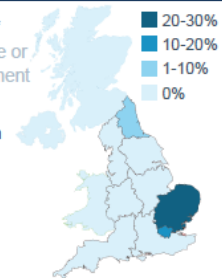
- ESCMID/ERS guidelines for CPA (Denning *et al*, 2016) recommend therapeutic drug monitoring (TDM) to reduce toxicity in patients receiving itraconazole, voriconazole or posaconazole
- Overall, around 62% did order TDM
- However, rates were much lower in West Midlands (20%), South East (47%), Yorkshire & Humber (43%).



Map shows the proportion of respondents who use TDM

Map shows the proportion of clinicians who use posaconazole or isavuconazole as first-line treatment

- Itraconazole is the most commonly used first-line antifungal in most areas, although some regions preferred voriconazole
- Newer azoles (posaconazole and isavuconazole) were sometimes selected for first-line treatment around London, the North East and the East of England



Which antifungals are prescribed?

Conclusions

Despite ESCMID/ERS recommendations, TDM is often not being used for azoles

Use of newer specialist fungal diagnostics (e.g. HVC and *Aspergillus* PCR) is low in many areas of the UK

Newer azoles are widely used in London/EofE, but older ones (voriconazole, itraconazole) are still preferred in most regions

Not sure how/where to order fungal tests?

Contact the Mycology Reference Centre Manchester
UKAS Lab No 10196 www.MRCM.org.uk
(also located at Wythenshawe Hospital, part of MFT)



- Mould/yeast ID: culture, HVC, seq, HVS
- TDM: flucytosine, fluconazole, itraconazole, voriconazole, posaconazole, isavuconazole
- PCR: *Aspergillus*, *Candida*, panfungal, *Pneumocystis*

Facebook support groups

The National Aspergillosis Centre Support (UK) group is our largest with 2873 members (the year to 23rd Sept 2023) and 213 new members approved. 1625 members were active with 661 original posts, 6902 comments, 9360 reactions. This represents an 11% increase in activity since 2023.

43% of our active audience are from the UK, 76% are women and 6/10 of the top cities that use the group are UK cities.

Posts ?

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

Top posts ▼

By all ▼













Date	Post	Reach	Engagement
7/7/2024 10:43 AM	 We have been advised to move from the area we live in , how do you get your head around leaving an area and... Posted by	422	54
7/10/2024 11:28 PM	 Hi everyone :-) Just a quick question: Aspergillus Fumigatus - I know it's everywhere but I have been told especially to... Posted by	288	44
7/16/2024 3:23 PM	 Hello my husband died last month cause of death Disseminated Aspergillosis He was diagnosed with CPA... Posted by	379	76
7/20/2024 9:05 PM	 Inspiration post Today I hiked 27.5 miles for macmillan in 8hrs and 27mins. Currently so well and loving life. Kind of... Posted by	561	126
6/28/2024 11:12 PM	 Hello friends. My analyzes indicate insufficient vitamin D due to prednisolone. Does anyone know what daily dose ... Posted by	225	31
7/6/2024 10:58 AM	 I'm nebulising Colomycin for a pseudomonas infection. Can anyone share similar experiences? Posted by	230	29
6/25/2024 4:58 PM	 Hi all, I'm just wondering if anyone is taking antihistamines with their fungal meds? It's allergy season and I've not... Posted by	198	36
7/4/2024 12:51 PM	 Morning all, sat here waiting for specialist to phone me. ABPA no other conditions , CT scan showed slight... Posted by	238	28
6/27/2024 10:10 PM	 Has anyone who's taken vorocnizole had problems with numbness in there feet Posted by	243	25
7/7/2024 12:32 PM	 Hi everyone, I'm about to start the new treatment for my severe asthma, I'm going to have the 4 weekly injection of... Posted by	221	23
7/2/2024 5:06 PM	 Hi all, thank you for letting me join. I have recently been diagnosed with ABPA, to go along with my COPD and... Posted by	513	21
7/16/2024	 44 weeks wait time from date of referral for the cough doctor. Will see them next year then... Posted by	625	22

Fig 1. Many posts are very popular, reaching hundreds of group members

12 Raising public awareness and educational outreach

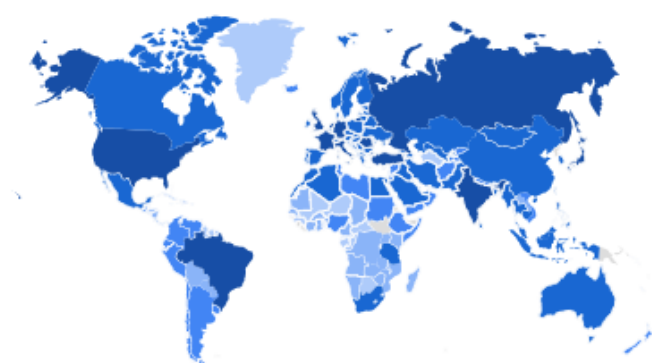
Aspergillosis Patients and Carers Website (aspergillosis.org)

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

Since July 2023 the website has been viewed 223 000 times and had 47 000 users, so we have recorded fewer users since the year before, but they have viewed more pages. Part of this dip in user numbers is technical, as we were unable to record site statistics from September 2023 until March 2025 i.e. half the year! This seem to have been caused by a software incompatibility problem.

In the Patients annual survey 2024 35% of all NAC patients had visited aspergillosis.org. 100% were satisfied or very satisfied with the website content.

Users ▾ by Country



<u>COUNTRY</u>	<u>USERS</u>
United Kingdom	3.7K
United States	2.8K
Russia	2.6K
France	1.9K
Germany	1.5K
India	1.5K
Italy	1.4K

[View countries](#) →

Map shows the numbers of people accessing aspergillosis.org over the last month (July 2024). The website is available in multiple languages. People from 191 countries have visited since July 2023.

YouTube

The YouTube channel plays a crucial role in extending the reach of educational efforts. Recordings from our monthly support meetings and World Aspergillosis Day are uploaded to our YouTube channel, so that they are available for patients who could not attend the meetings.

In autumn 2024, we began separating the recordings into individual talks and redesigned our thumbnail graphics, which has led to a noticeable increase in the number of views they receive.

www.youtube.com/@nationalaspergillosiscentr4264



MicroRNAs - can we target them to diagnose, monitor & treat aspergillosis?
48 views • 2 weeks ago



How can you find a health tracker app that's secure, accurate, useful and easy to use?
24 views • 2 weeks ago



SELF BREATHE: clinical trial for a breathlessness management app
24 views • 2 weeks ago



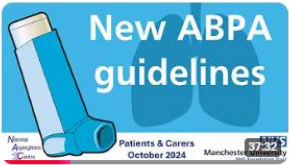
Medications in the pipeline - can blocking IL-11 help to reduce lung scarring (fibrosis)?
408 views • 1 month ago



Sepsis Awareness Month - symptoms, causes, getting help, recovering
182 views • 1 month ago



Are YOU undefeatable? Finding manageable ways to stay active with a long-term health...
39 views • 1 month ago



ISHAM's new ABPA guidelines - what changed and why? (staging, biologicals,...
398 views • 1 month ago



Respiratory viruses this winter: COVID, flu, RSV & more
55 views • 1 month ago



Functional medicine: What is it? Who is it for? How can I try it safely?
90 views • 1 month ago



Keeping your dental microbiome healthy to protect your lungs (National Aspergillosis...
153 views • 1 month ago



Monthly Patient & Carer Meeting - July 2024
111 views • 5 months ago



Complex Breathlessness: Inducible Laryngeal Obstruction
190 views • 5 months ago

Education

The CARES team and NAC fellows with NAC consultant Chris Kosmidis have partnered with MIMS Learning ([mimslearning.co.uk](https://www.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.

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. Financial Position

Redacted in web version

14. Future Service Developments

The following developments are planned for 2023/2024:

1. Equitable access to the NAC

Equitable access to the NAC for all patients with CPA in England and Scotland is the priority for the coming years. Although the NAC cares for patients from all parts of England and Scotland, historically, patients from the Northwest have been overrepresented (see Appendix 2). We have been working to raise awareness of CPA among clinicians and the public and we are working together with NHSE to address this through a hub and spoke model.

2. Focus on patient reported outcomes and quality of life

Quality of life is significantly affected in CPA patients and treatment has been shown to improve this. Monitoring of the impact of CPA on quality of life has always been a priority for the NAC. This has been happening through the use of the St George's quality of Life questionnaire and this forms part of the reporting requirements. Due to challenges in collecting this questionnaire (due to remote consultations and also due to the complexity; it consists of >50 questions) we have moved to reporting of CT scans and Aspergillus serology instead during the pandemic. However we believe patient reported quality of life should be at the centre of CPA management and be available to patients and treating physicians alike to inform treatment decisions and patient experience. As a QIP, we have started recording a respiratory questionnaire, the CAT score, for patients with CPA as part of their clinic visit. The ultimate goal is to make this questionnaire available to clinicians during the encounter to improve the consultation process and patient experience. In addition, the NAC participates in the CAPSULE study, sponsored by Imperial College, that will develop a new Patient Reported Outcome Measure in CPA.

3. Implementation of an annual review process

Antifungal treatment requires close supervision with therapeutic drug levels and toxicity monitoring. We aim to introduce a rolling audit of the adequacy of TDM and actions, as well as an audit of drug interactions of azole agents in our patients.

4. Obtain support for the NAC MDT by a Consultant Thoracic Radiologist

The NAC MDT would greatly benefit from participation of a Consultant Thoracic Radiologist. Most patient discussions and decisions regarding treatment effectiveness in CPA involve review of a chest CT scan. Presence of a radiologist with real time review of imaging would

enable more robust decisions on CPA treatment. This would require funding for 4 hours per week of a consultant's time.

5. Understanding the role of new antifungals in CPA

Azoles (itraconazole, voriconazole, posaconazole, isavuconazole) are still the only class of oral antifungals with useful activity in CPA. They are associated with toxicity and require close monitoring. Resistance and intolerance are common, leaving intravenous antifungals as the only option in some patients. New options are clearly needed.

Several antifungals with activity against *Aspergillus* are close to approval: ibrexafungerp received orphan drug status from the European Medicines Agency in 2021, rezafungin, a once-weekly IV antifungal received FDA approval in 2023, olorofim is under review by the FDA, and fosmanogepix has received fast track indication by FDA. All of these agents are promising for the treatment of CPA once approved. We aim to follow developments and new data closely in order to determine the role of these agents in CPA for patients who do not benefit from current treatments. We have been selected as a site for a clinical trial on rezafungin, a novel once-a-week antifungal for CPA.

6. Understanding the genetic background of CPA

Our research has shown evidence of immune system defects in patients with CPA. These are suspected to be linked to genetic defects which remain unrecognised. Identifying those genetic defects will help us understand the causes of CPA as well as potentially have diagnostic implications. We are collaborating with the Manchester Fungal Infection Group via PhD project to recruit patients via a biobank to explore this.

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

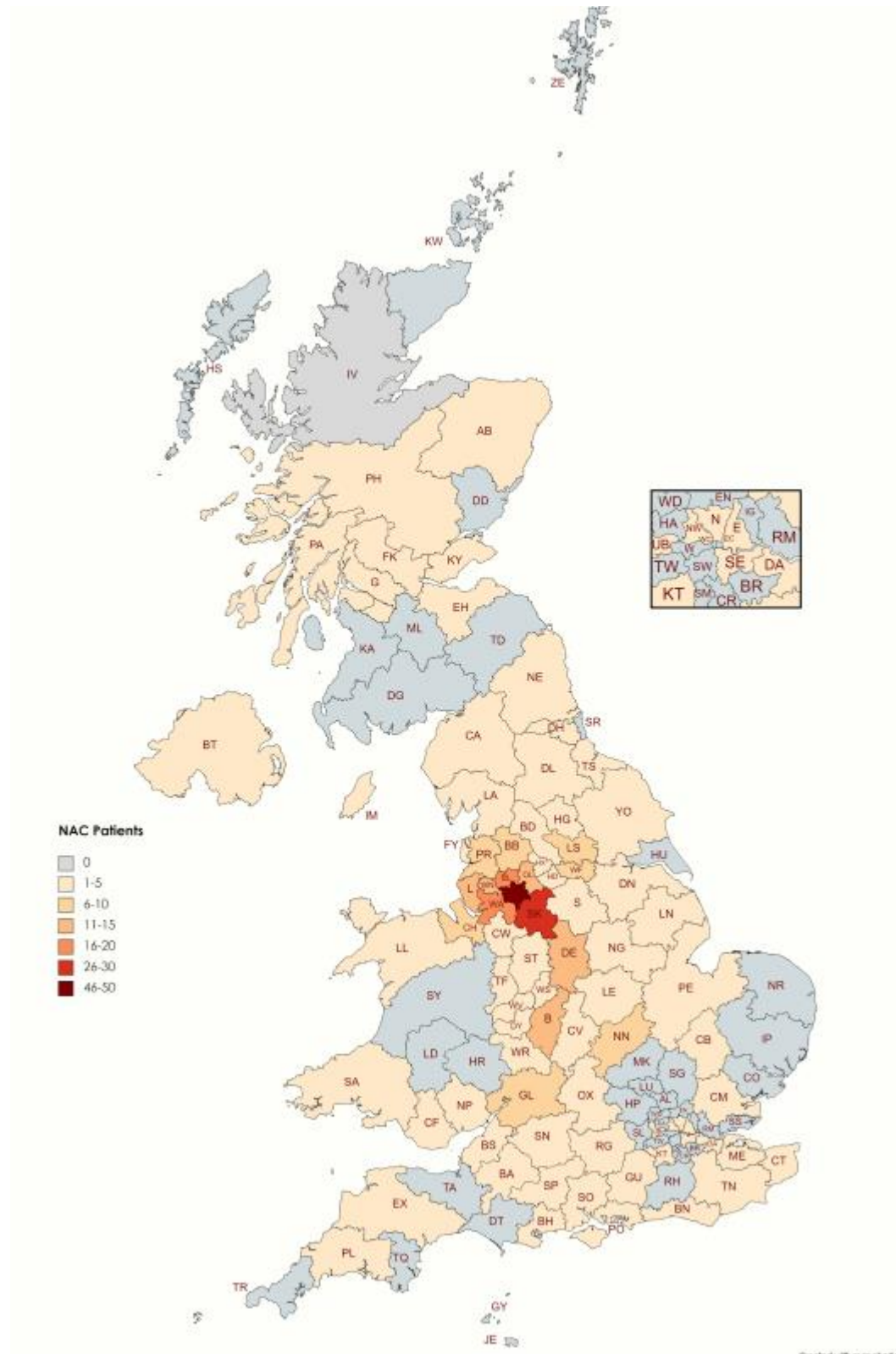
- Significant impairment of respiratory function, sufficient to impair activities of daily living, but ambulant
and/or
- Concurrent anti-mycobacterial treatment
and/or
- Failed or developed toxicity to itraconazole capsules
and
- No evidence of azole antifungal resistance

Stage 3

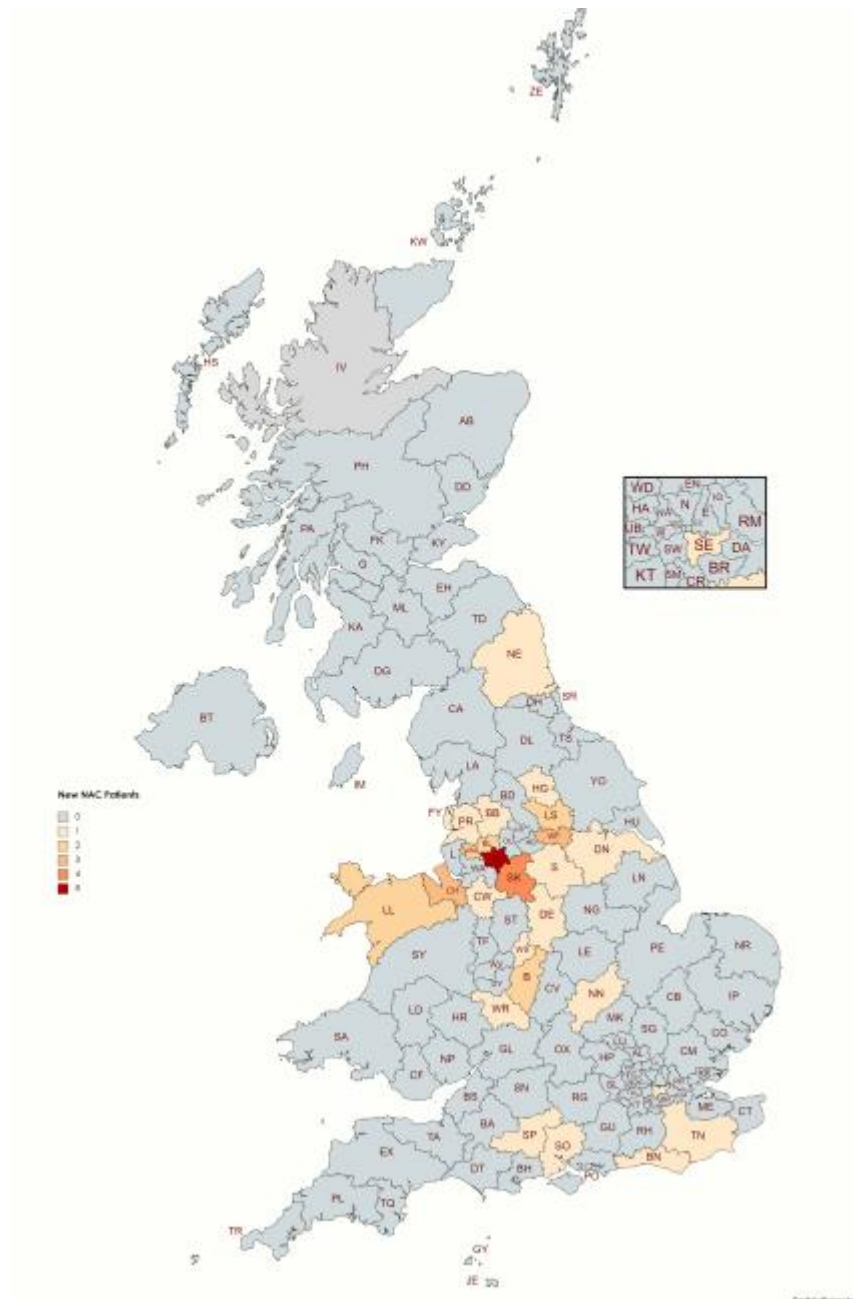
- Antifungal azole resistance documented
and/or
- Long term nebulised or IV antibiotic treatment required (bronchiectasis, Pseudomonas colonisation)
and/or
- Wheelchair bound
and/or
- HIV infected
and/or
- Severe hepatic or renal disease

Appendix 2 Geographical location of patients attending NAC

Graph 1. All patients on NAC service in March 2023



Graph 2. New patient referrals 2022-2023



Appendix 3 Publications

NAC/MRCM Journal publications 2023-2024.

Arendrup, M.C. et al. (2023) ‘European candidaemia is characterised by notable differential epidemiology and susceptibility pattern: Results from the ECMM Candida III study’, *The Journal of Infection*, 87(5), pp. 428–437. Available at: <https://doi.org/10.1016/j.jinf.2023.08.001>.

Armstrong-James, D., Kosmidis, C. and Bromley, M. (2023) ‘Update on the treatment of chronic pulmonary aspergillosis’, *Current Opinion in Infectious Diseases*, 36(2), pp. 146–151. Available at: <https://doi.org/10.1097/QCO.0000000000000913>.

Arts, R.J.W., Janssen, N.A.F. and van de Veerdonk, F.L. (2023) ‘Anticytokine Autoantibodies in Infectious Diseases: A Practical Overview’, *International Journal of Molecular Sciences*, 25(1), p. 515. Available at: <https://doi.org/10.3390/ijms25010515>.

Carter, C. et al. (2024) ‘Chronic pulmonary aspergillosis - a guide for the general physician’, *Clinical Medicine (London, England)*, 24(1), p. 100019. Available at: <https://doi.org/10.1016/j.clinme.2024.100019>.

Eades, C.P. et al. (2023) ‘Comparison of β -1-3-D-Glucan and Candida Mannan Biomarker Assays with Serological Tests for the Diagnosis of Candidemia’, *Journal of Fungi (Basel, Switzerland)*, 9(8), p. 813. Available at: <https://doi.org/10.3390/jof9080813>.

Egger, M. et al. (2023) ‘Predictors for Prolonged Hospital Stay Solely to Complete Intravenous Antifungal Treatment in Patients with Candidemia: Results from the ECMM Candida III Multinational European Observational Cohort Study’, *Mycopathologia*, 188(6), pp. 983–994. Available at: <https://doi.org/10.1007/s11046-023-00776-4>.

Evans, T.J. et al. (2024) ‘Chronic Pulmonary Aspergillosis: Clinical Presentation and Management’, *Seminars in Respiratory and Critical Care Medicine*, 45(1), pp. 88–101. Available at: <https://doi.org/10.1055/s-0043-1776914>.

Gangneux, J.-P. et al. (2024) ‘Knowledge and regulation on fungal contamination of sand and water: Progress report and perspectives’, *Medical Mycology*, 62(2), p. myad137. Available at: <https://doi.org/10.1093/mmy/myad137>.

Hoenigl, M. et al. (2023) ‘Guideline adherence and survival of patients with candidaemia in Europe: results from the ECMM Candida III multinational European observational cohort study’, *The Lancet. Infectious Diseases*, 23(6), pp. 751–761. Available at: [https://doi.org/10.1016/S1473-3099\(22\)00872-6](https://doi.org/10.1016/S1473-3099(22)00872-6).

Kanj, S.S. et al. (2023) ‘The battle against fungi: lessons in antifungal stewardship from COVID 19 times’, *International Journal of Antimicrobial Agents*, 62(1), p. 106846. Available at: <https://doi.org/10.1016/j.ijantimicag.2023.106846>.

Khateb, A. et al. (2023) ‘Aneuploidy Is Associated with Azole Resistance in *Aspergillus fumigatus*’, *Antimicrobial Agents and Chemotherapy*, 67(4), p. e0125322. Available at: <https://doi.org/10.1128/aac.01253-22>.

Kosmidis, C. et al. (2023) ‘Impact of self-reported environmental mould exposure on COPD outcomes’, *Pulmonology*, 29(5), pp. 375–384. Available at: <https://doi.org/10.1016/j.pulmoe.2021.05.003>.

Kosmidis, Chris et al. (2023) ‘Predictive factors for treatment response and mortality in chronic pulmonary aspergillosis’, *Mycoses* [Preprint]. Available at: <https://doi.org/10.1111/myc.13641>.

Kosmidis, C. et al. (2024) ‘*Aspergillus* nodules: Natural history and the effect of antifungals’, *Mycoses*, 67(3), p. e13716. Available at: <https://doi.org/10.1111/myc.13716>.

Kosmidis, C. and Hoenigl, M. (2023) ‘COVID-19-associated pulmonary aspergillosis in mechanically ventilated patients: a deadly complication’, *Thorax*, 79(1), pp. 9–10. Available at: <https://doi.org/10.1136/thorax-2023-220621>.

Ocansey, B. et al. (2024) ‘A diverse spectrum of mycoses histologically diagnosed in Ghana: Insights from a 10-year retrospective study’, *Medical Mycology*, 62(3), p. myae015. Available at: <https://doi.org/10.1093/mmy/myae015>.

Ocansey, B.K. et al. (2023) ‘Invasive Aspergillosis among Haematological Malignancy Patients in Ghana: A Pilot Study on Prevalence and Antifungal Prophylaxis at the National Referral Hospital’, *West African Journal of Medicine*, 40(6), pp. 613–618.

Rozaliyani, A. et al. (2023) ‘The Fungal and Bacterial Interface in the Respiratory Mycobiome with a Focus on *Aspergillus* spp’, *Life* (Basel, Switzerland), 13(4), p. 1017. Available at: <https://doi.org/10.3390/life13041017>.

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Appendix 4 Patient Survey Results

NAC clinics remain only partially face-to-face with most patients seen remotely we have again offered this survey in a variety of ways in order that every patient was given an opportunity to complete it. F2F 132 (30%), Video 58 (13%), Phone 209 (47%), New (presumably F2F) 47 (11%).

We used Accurx internet services to send all patients a text message offering a link to the survey and phone number so that they could complete the survey with our assistance over the phone.

The patient's survey was offered from May 3rd to June 28th, which was a total of 446 patients. No patient used the phone to complete the survey.

Of those, 26 patients (5.3%) responded and completed a survey. This is slightly less than we received in 2023 (when there were 29 surveys completed).

Survey responses

The number of responses was slightly less than in 2023 (26 vs. 29) and form the latest part of a downwards trend. We have tried shortening and simplifying the survey and last year suggested that we might start asking patients face-to-face in clinic in an effort to increase numbers but we were unable to do that this year due to staffing limitations i.e. it would take a whole day to offer the survey to all patients in a clinic.

We have also talked about sending out electronic versions of the survey via myMFT but that would have presented more barriers to the person attempting to complete a survey i.e. they would need to print it out and post in back to us, so that didn't seem to be the answer.

One solution that has worked in the past is posting out paper copies of the survey but that is also time consuming, unless there is a way that it can be automated via HIVE.

Action points

Action point A: 4/26 (0% in 2023) patients were unsatisfied or worse with a virtual consultation. Of the 4 patients who were unsatisfied, 1 had cancelled appointment, 1 missed their appointment, 1 was not offered a virtual appointment and 1 did not comment

Response: Systems communicating appointments to patients could be reviewed/audited to establish if there are any weak points, but any problems are at a low level.

Action point B: In 2023 videoconferencing was only chosen by half as many patients as a preferred option. In 2024 this has increased proportionally, and all four options are now equally represented, perhaps as patients become more familiar with videoconferencing software or have more access to the equipment needed?

We are going to have to maintain all options for the foreseeable future – clinics currently operate with up to 40% F2F consultations (including new patients) and maybe some of those would prefer a virtual meeting

Response: To meet the needs of all patients, we should maintain the offer of video consultations where possible.

Action point C: All patients were 100% satisfied or better with courtesy shown by all team specialities except for one patient who was unsatisfied with the courtesy shown by CARES

team. The patient did not comment about this specifically but did complain repeatedly about a cancelled appointment.

Response: There does not seem to be a specific complaint regarding the CARES team, but we should be reminded to ensure all patients are satisfied after an interaction with staff.

Action point D: Four staff groups received one expression of dissatisfaction about communication and care:

Aspergillosis Specialist (no patients comment)

Doctors (patient comment 'doctor was rude')

CARES team & Admin team (patients comment (i.e. the same patient about both teams) 'My appt was cancelled. No notice no letter received. I have told PALS. So its going through that channel.')

Response: It is difficult to think of constructive suggestions to address the first two of these complaints. We can inform the groups involved for their own information and to ask them to make all team members aware of this complaint for future consideration.

The comment about the CARES and Admin team is a little more constructive – we should check if appointment cancellations are adequately communicated to the patient according to the patient needs. Perhaps review/audit patient experiences?

This patient's comment does not seem to relate to CARES team activities so it is only possible to make all members of the team aware of this complaint for future consideration.

Action point E: 92% (97% 2023) patients were satisfied or better with communications regarding clinic appointments. Patient comments by those who were unsatisfied mention appointment cancellations as a possible cause.

Direction to clinic 3 entrance and parking would have been helpful.

I wasn't told it was cancelled. I had a letter telling me I had an appt

Rang to cancel and rearrange but not answered

Response: There seem to be a few issues with communication about appointments, so it might be worth reviewing procedures to check that they are robust.

Additional note – providing more information to first time patient e.g. about travel and car parking prior to them travelling, might be worthwhile for some.

Action point F: A very similar proportion of patients received a leaflet on antifungal side effects (52% 2023), but this is still significantly down on 2021 (76%).

Response: There has been much improvement with this, but more work is needed to restore us to 2021 levels of leaflet distribution.

Action point G: 88% (93% 2023) understood questions to answers that they had asked of the NAC team. 3 patients did not agree that they understood NAC staff answers to their questions.

Response: All staff should be aware that a few patients may not be understanding clearly your answers to their questions, even if they say that they do. Ensure that all patients are guided to CARES team for further information & guidance if appropriate.

Action point H: 23% (45% 2023) accessed physio online materials, a significant drop.

A patient commented:

Not made available for me

Response: This may or may not be intended, but provides a point for Physio team to address.

Action point I: One patient would not recommend Wythenshawe Hospital to friends and family. The patients who answered no did not offer a critical comment to explain why, however this comment gives us some scope for an improvement in patient service: With reservation. I had a difficult time finding out where the Lung Centre was. Signage was not good and most of the staff in the passages I asked didn't have a clue where the Lung centre was

Response: Ensure all new patients are more efficiently guided to the Lung Centre and improve awareness of the lung centre amongst staff at Wythenshawe.

Action point J. Postal service for blood & sputum tests

The plastic lids of the container for the pot doesn't close properly

Response : Check pots work as intended

Action point K. aspergillosis.org website

If you have not visited the website is there a reason why?

Was not made aware of it and will have a look now

Not aware of it

Didn't know anything about it

I have never heard of it, didn't know it existed

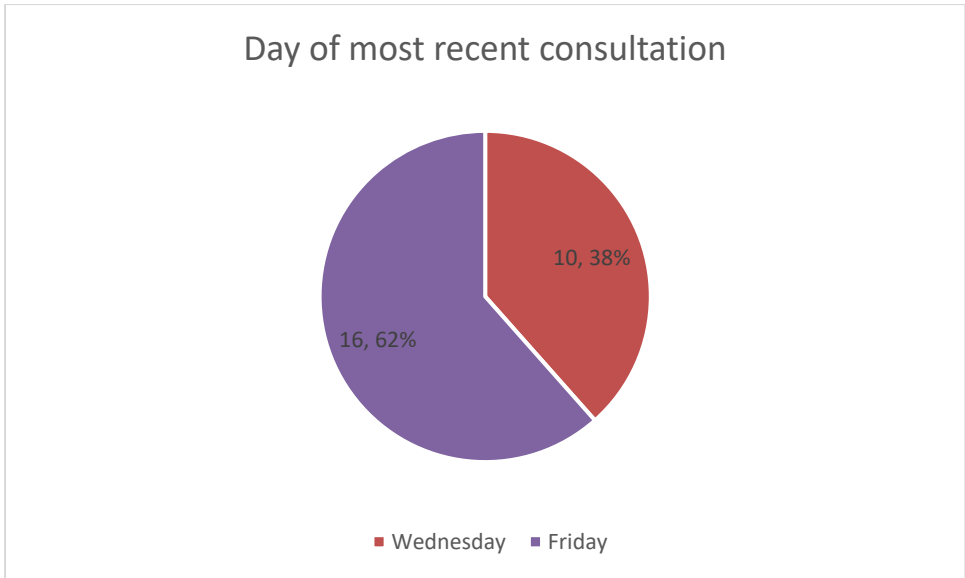
I don't know how to visit

Didn't realise there was one

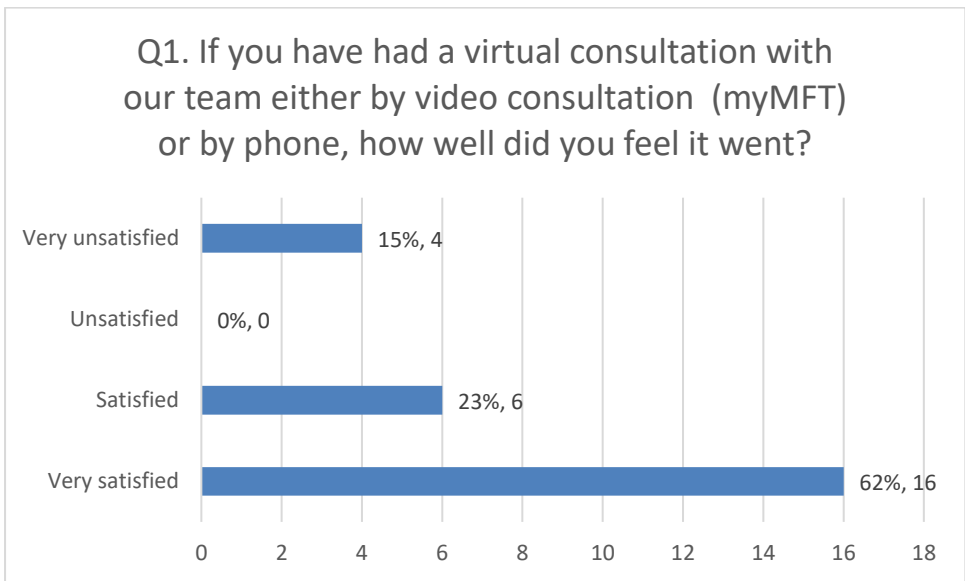
Response: Several patients do not know about aspergillosis.org website despite all patients being texted about the website after every appointment at NAC over the last year. CARES team to review the text message and possibly provide paper copies of support & resources offered in clinic.

Conclusions

The National Aspergillosis Centre performs extremely well and that is thanks to its excellent staff. There have been a few small areas of weakness identified by this survey but they are very small. Comparing with the Patient Survey 2023 there are also areas where we are clearly improving thanks to our creativity and drive to improve.

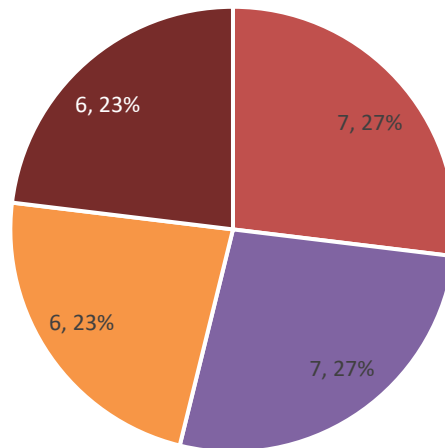


62% of respondents attended a Friday clinic, 38% Wednesday.



4/26 (0% in 2023) patients were unsatisfied or worse with a virtual consultation. Of the 4 patients who were unsatisfied, 1 had cancelled appointment, 1 missed their appointment, 1 was not offered a virtual appointment and 1 did not comment. *Action point A*

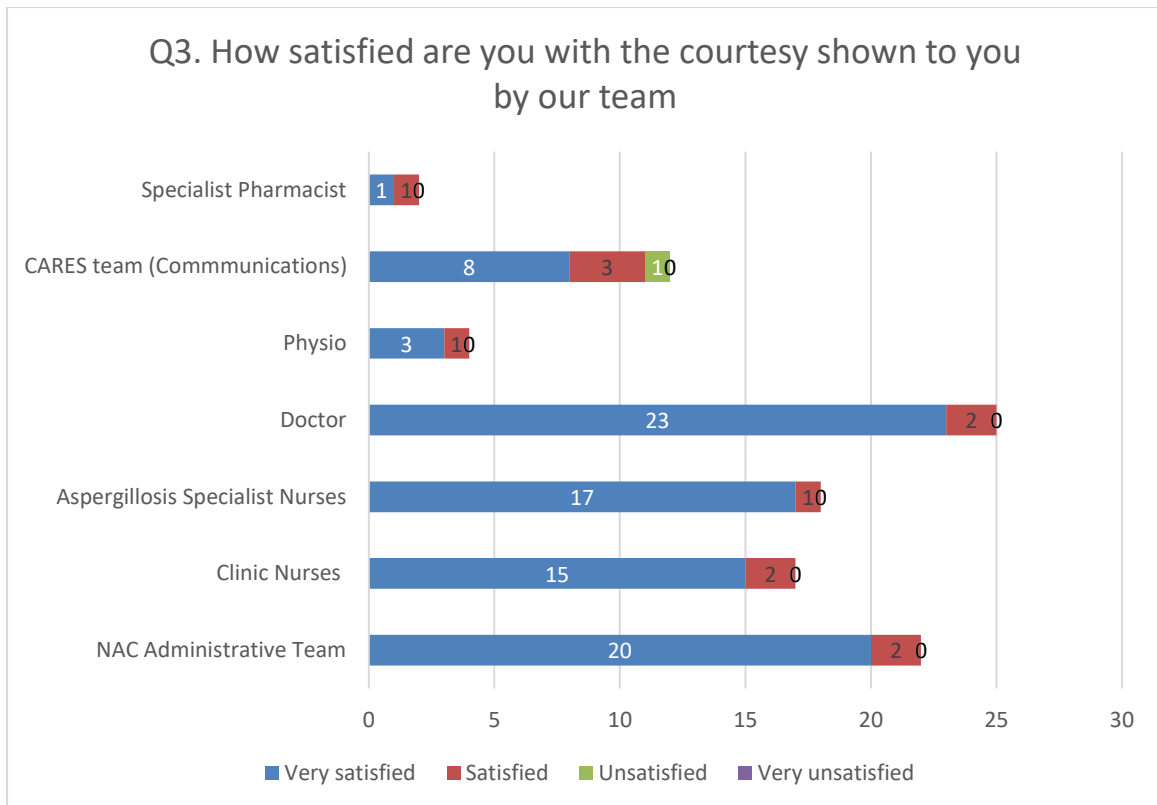
Q2. If you were given the choice in the future, would you choose to have your consultations face to face at Wythenshawe Hospital, by video consultation or by telephone consultation?



- Videoconference
- Phone
- Face-to-face in clinic
- A mixture of face-to-face and video depending on symptoms

In 2023 videoconferencing was only chosen by half as many patients as a preferred option. In 2024 this has increased proportionally, and all four options are now equally represented, perhaps as patients become more familiar with videoconferencing software or have more access to the equipment needed?

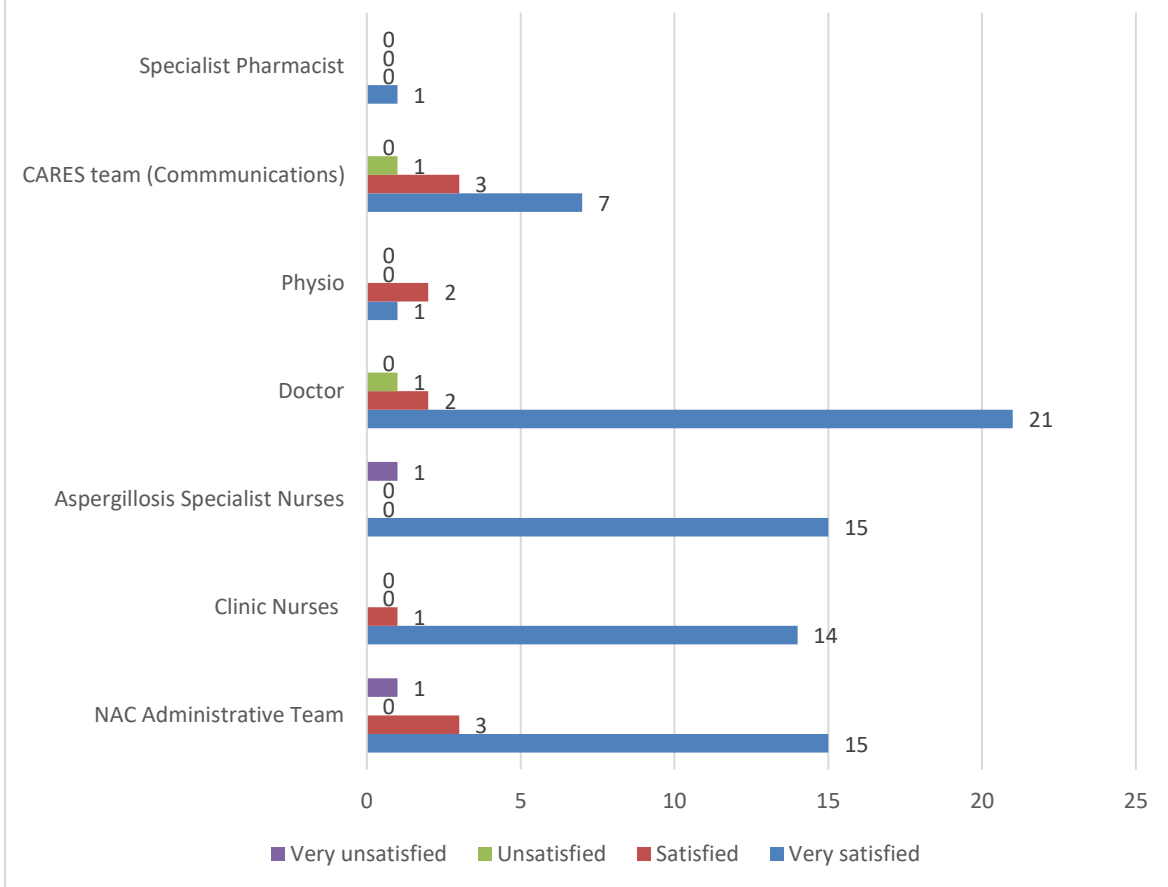
We are going to have to maintain all options – clinics currently operate with up to 40% F2F consultations (including new patients) and maybe some of those would prefer a virtual meeting *Action point B*



All patients were 100% satisfied or better with courtesy shown by all team specialities except for one patient who was unsatisfied with the courtesy shown by CARES team. The patient did not comment about this specifically but did complain about a cancelled appointment.

Action point C

Q4. How satisfied were you with the communication and care provided by each member of the NAC team?



Satisfaction for most staff groups in 2024:

NAC Admin 95% satisfied or better (96% 2023)

Clinic Nurses 100% satisfied or better (96% 2023)

Aspergillosis Specialist Nurses 94% satisfied or better (96% 2023)

Doctors 96% satisfied or better (93% 2023)

Specialist Physiotherapists 100% satisfied or better (85% 2023)

CARES Team 91% satisfied or better (92% 2023)

Specialist Pharmacist 100% satisfied or better (100% 2023)

Q4 Patient comments

All excellent...

My appt was cancelled. No notice no letter received. I have told PALS. So its going through that channel.

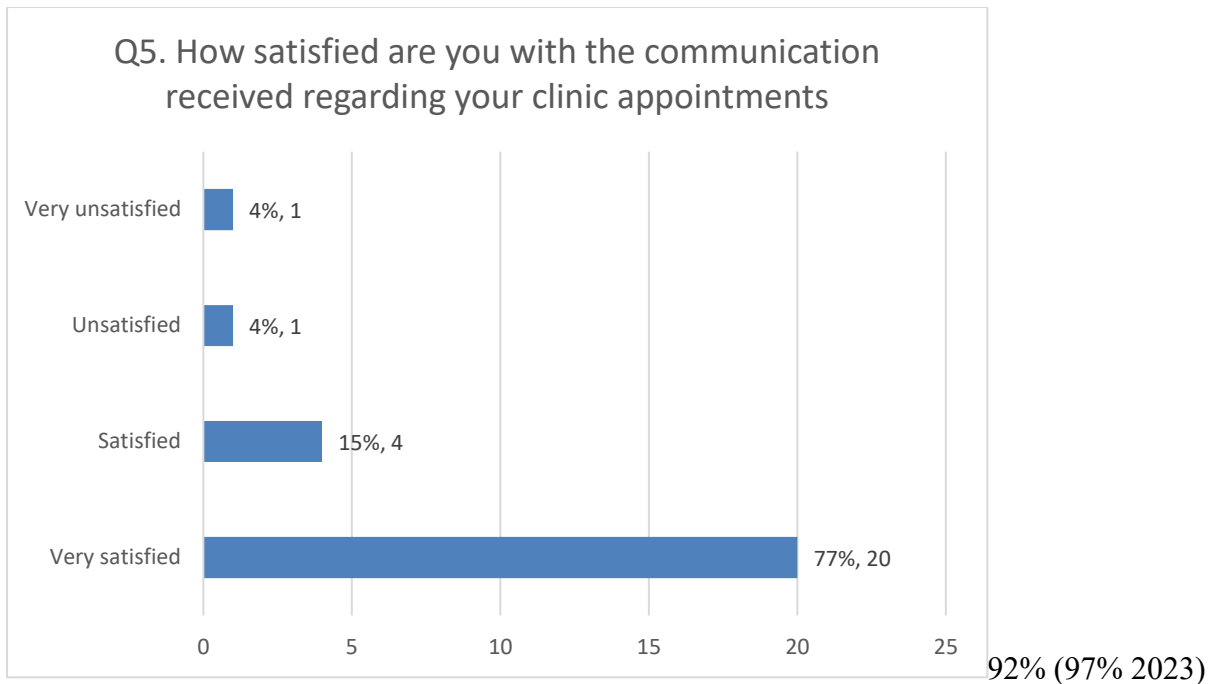
10 out of 10

Have not had the full support of the team because I live out of area

I join the NAC group on Tuesday afternoons

Doctor was rude

Action point D



patients were satisfied or better with communications regarding clinic appointments. Patient comments by those who were unsatisfied mention appointment cancellations as a possible cause.

Q5 Patient comments

Direction to clinic 3 entrance and parking would have been helpful.

I wasn't told it was cancelled. I had a letter telling me I had an appt

V good

Received my appointments with good notice

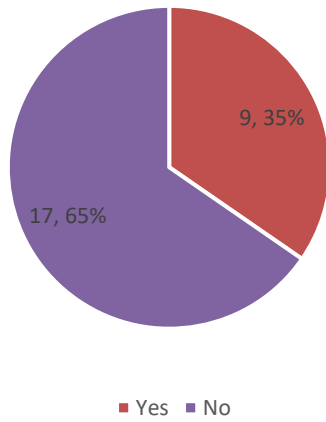
Rang to cancel and rearrange but not answered

The letter contains info about how to join the video consultation

Very good

Action point E

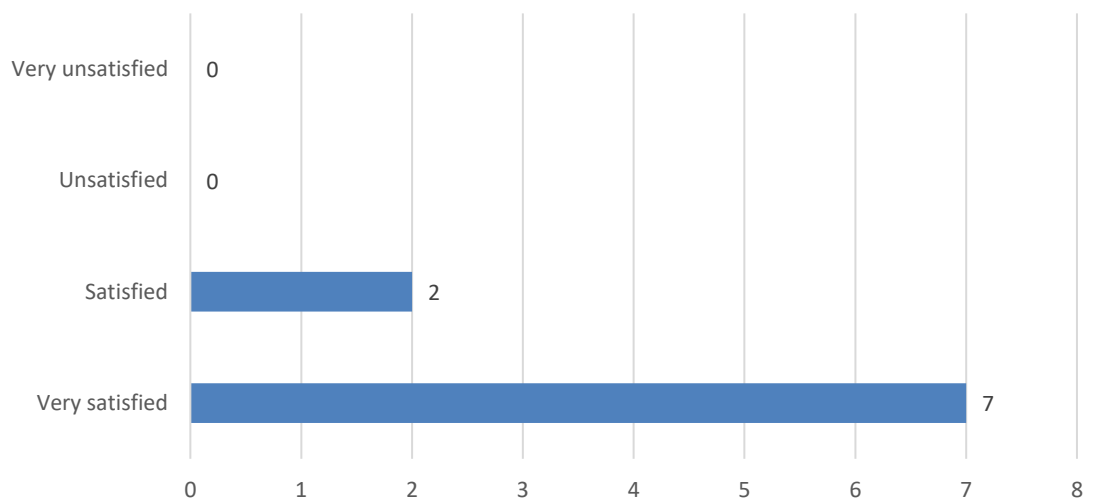
Q6. Have you had a consultation in-between clinic appointments with one of our specialist nurses?



35%

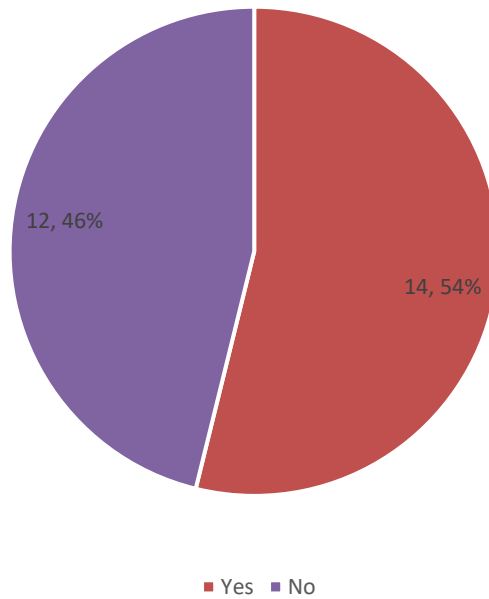
had a consultation in-between clinic appointments – an increase on 2023 (25%)

Qa. Knowledge of condition



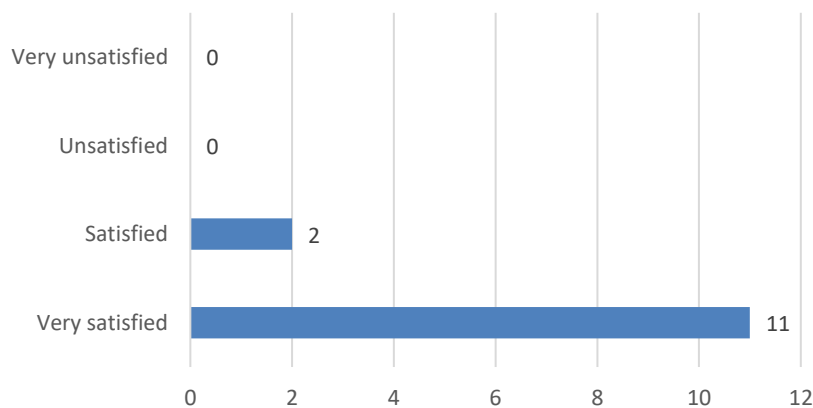
Of those who had had a consultation in-between clinic appointments, 100% were satisfied or better with the communication offered.

Q7. Have you received any information (e.g. leaflets, website) about your condition?



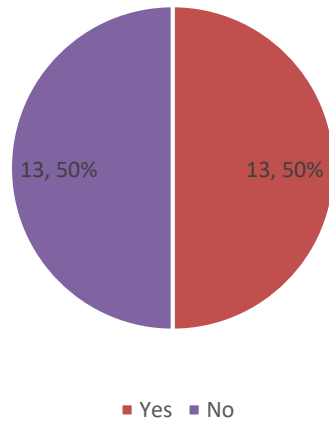
54% (34% 2023) of patients received information, a significant increase.

7a. How satisfied are you with the information you received about your condition?



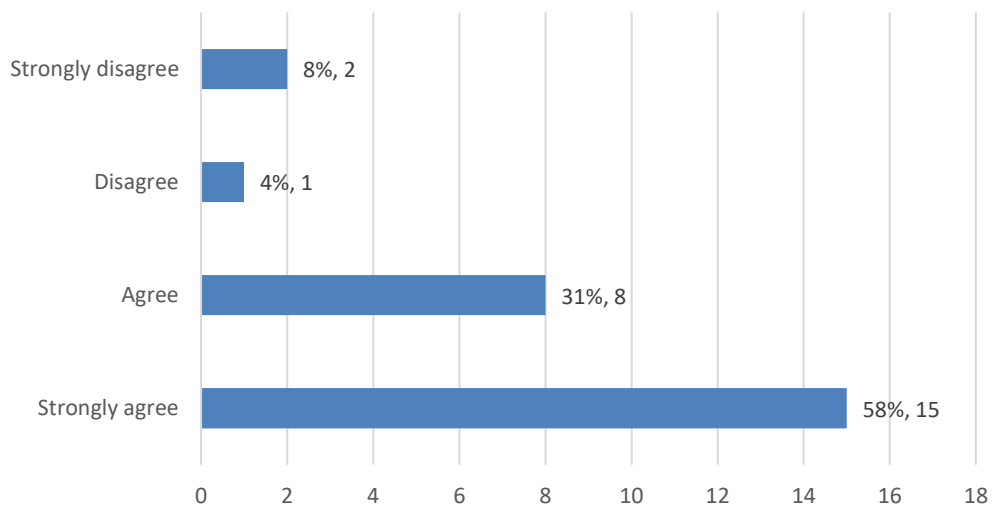
100% were satisfied or better (100% 2023).

8. If you have used antifungal medication, did one of our team members tell you about or give you a leaflet about possible side effects of this medication?



A very similar proportion of patients received a leaflet on antifungal side effects (52% 2023), but this is still significantly down on 2021 (76%). *Action point F.*

Q9. When you had questions to ask a member of the NAC team did you get answers that you could understand?



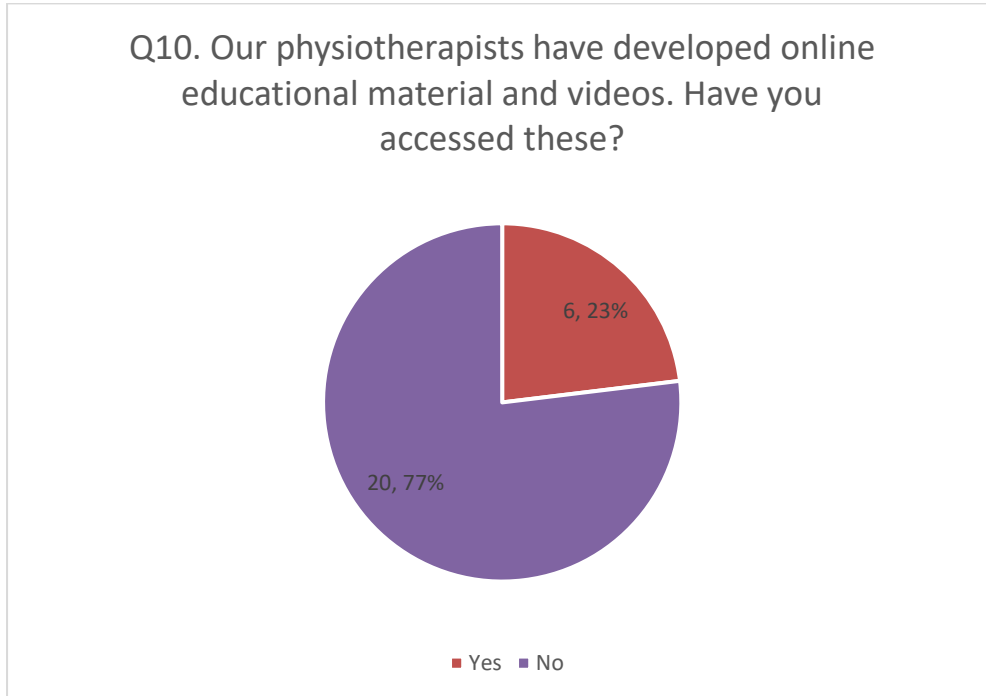
88% (93% 2023) understood questions to answers that they had asked of the NAC team.

Q9 Patient comments

Excellent communication.

Unable to answer but had to click a box (Editors comment – this comment refers to one of the two ‘strongly disagree’ replies).

Action point G



23% (45% 2023) accessed physio online materials, a significant drop.

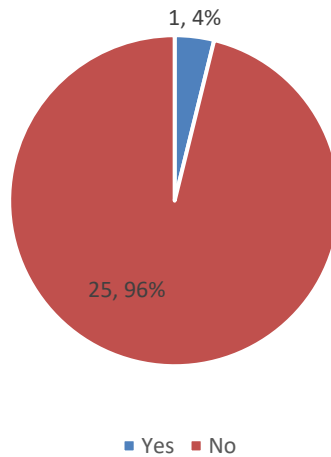
Q10 Patient comments

Not made available for me

Breathing exercises are useful

Action point H

Q11. Have you had an in-patient stay at Wythenshawe Hospital within the last year for treatment of your aspergillosis? For example to undergo surgery, intravenous antifungals or a procedure to stop bleeding from the lungs?

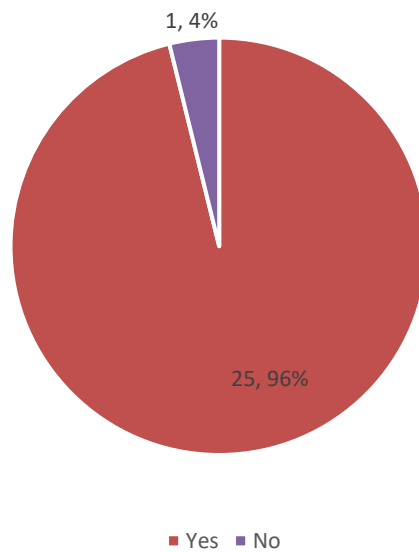


4% patients had an inpatient stay (0% 2023). This patients stated that they had been treated with respect and dignity during their stay.

Q11 Patient comment

I'm glad with the treatment with respect

Q12. Would you recommend Wythenshawe Hospital to friends and family?



96% would recommend Wythenshawe to friends and family (94% 2023).

Patient comments

Clinical members always responsive , providing useful advice and feedback on clinical condition and medical progress.

I feel very satisfied and grateful for the care received.

Always treated with professionalism and understanding

Excellent standards of diagnosis by properly qualified doctors.

The best at Aspergillosis care. But we need to be told to have a local asthma hospital clinic hospital as well.

V good hospital

Was looked after very well during my visit

A specialist ABPA team

Face to face appointments have always been prompt and efficient and I have confidence in the knowledge of the staff and their competence.

The Doctors & nurses understand the what the patients are going through and being on their first appointment. I remember my first appointment in March 2014 and I was put at ease and going home I had a positive attitude on the outcome of the appointment and I still have that today.

No pt interaction with hospital so no reason not to. Professionally, through work, would def recommend

Everyone was polite and helpful and useful to see specialised staff

With reservation. I had a difficult time finding out where the Lung Centre was. Signage was not good and most of the staff in the passages I asked didn't have a clue where the Lung centre was

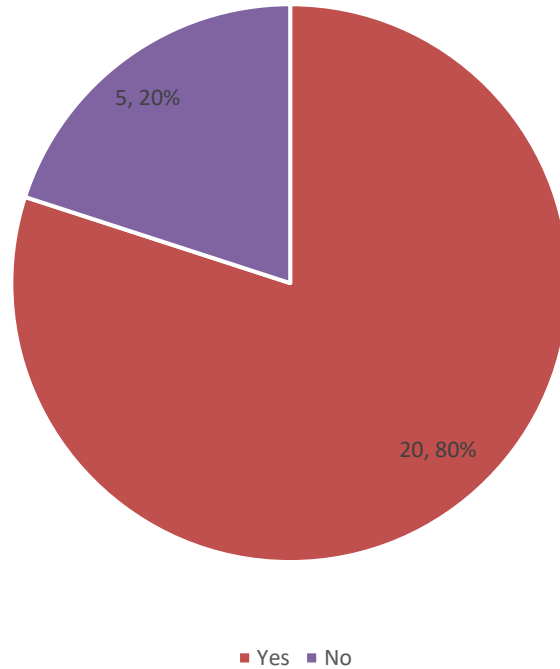
All the Nurses and Doctors and the people around the hospital is very kind and very friendly

Good service

Very helpful and caring

Action point 1

Q13. We provide a postal service for medication blood levels, aspergillus antibody levels and sputum samples.
Have you used this service over the last year?



80% used the postal service in 2024, which is an increase on 2023 (66%).

Q13 Patient comments

Very helpful, including follow up with clinical members to understand blood test results .

Very useful.

Sputum samples

I was passed on to Guys Asthma clinic

Seemed to work well - I hope it continues - my surgery seemed a bit confused to start with but eventually got everything requested done

Very useful

Not invited to

I have had drug levels done in conjunction with my GP practice

blood tests work very well

The plastic lids of the container for the pot doesn't close properly

Sputum sample at Leighton Hospital and Eagle bridge

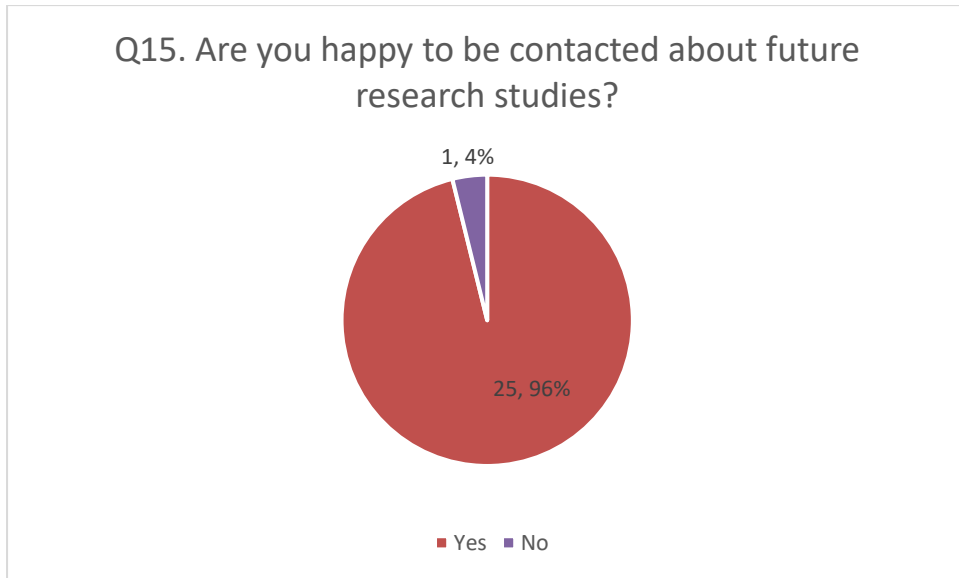
Action point J

Q14. We have commissioned a company to deliver certain antifungal medication to patient's homes. If you have received this service are you satisfied with it?

Yes fully satisfied with advice given and delivery service .

This would be very helpful but I have not been prescribed any further medication as yet

satisfied
Excellent reliable service.
I'm satisfied
Very happy
In the past very satisfied
Constantly messaging me to book a date before I need one



96% are happy to be contacted about future research studies (86% 2023)

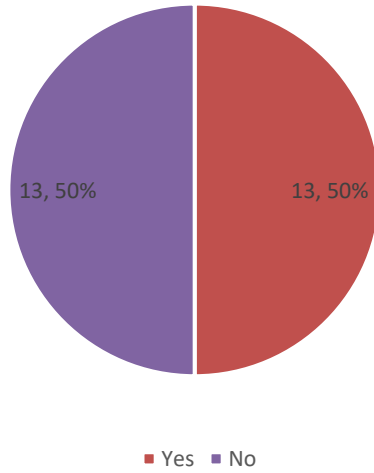


96% are happy with procedures and consent (100% 2023).

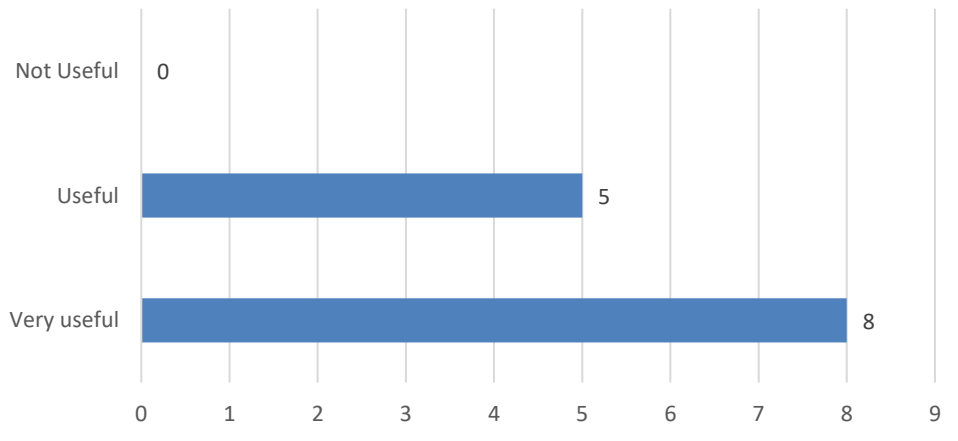
Patient comments

I have not met the criteria for any of the recent research studies
Great

Q16. We have developed patient information leaflets that are online at <https://aspergillosis.org/more/#leaflets-blog> and on request in clinic. Have you seen them?

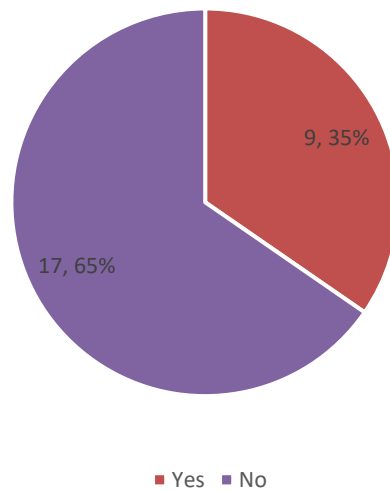


Q16a. If you have seen them, how useful do you think they were for you?



50% have seen online leaflets or in clinic (52% 2023) and 100% find them useful or better (100% 2023).

Q17. Have you visited the new Aspergillosis patient's and carers website? (aspergillosis.org)



35% have visited the aspergillosis.org website (31% 2023).

Q17b. If you have not visited the website is there a reason why?

Currently satisfied with level of support and ongoing anti-fungal medication.

Not seen the need.

Was not made aware of it and will have a look now

Not aware of it

I don't feel the need for further information at the moment

Didn't know anything about it

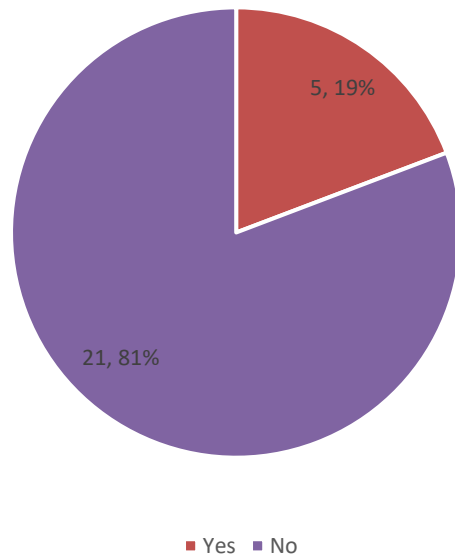
I have never heard of it, didn't know it existed

I don't know how to visit

Didn't realise there was one

Action point K

Q18. Have you attended the patient's meeting?



19% have attended a patient meeting online (21% 2023).

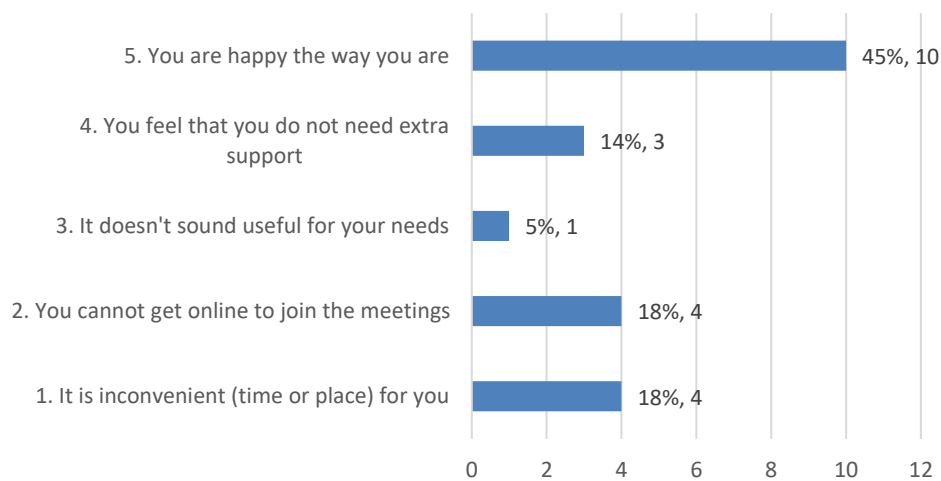
Always informative and friendly

It is really difficult to get into them. Just me probably.

Yes

Good

Q18b. If no, please tick the following comments if relevant



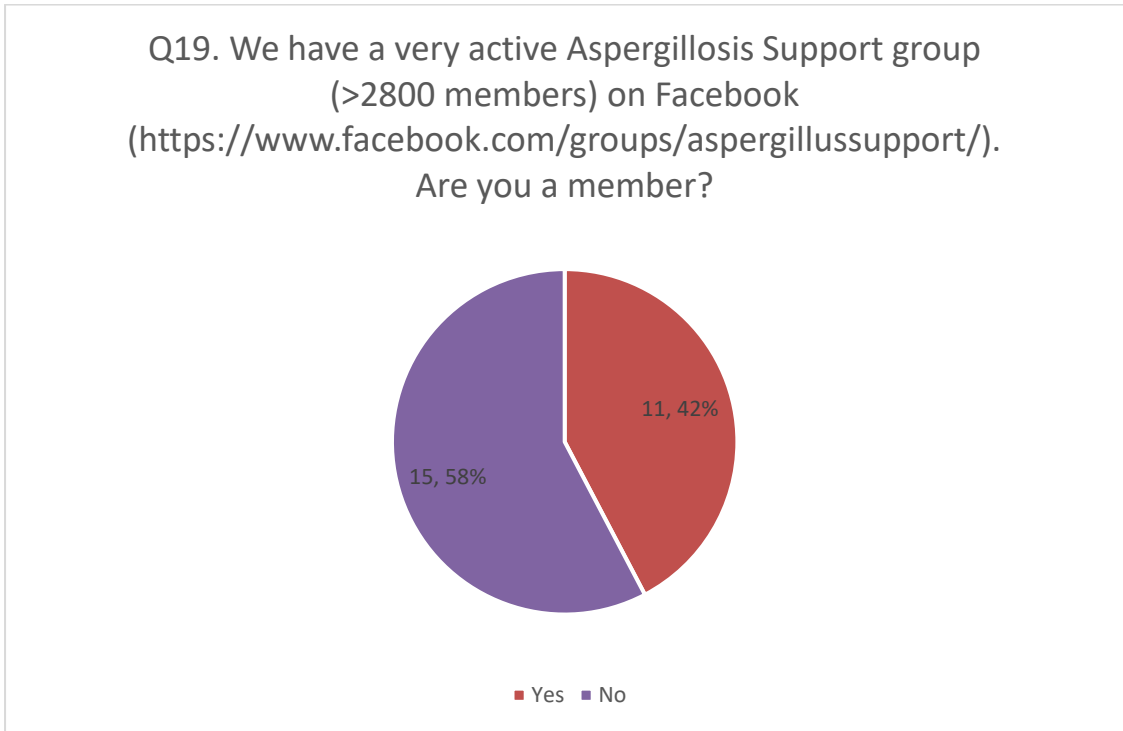
64% (73% 2023) did not feel that they needed this type of support. 36% did not have access the meetings e.g. cannot get online (27% 2023).

Q18 Patient comments

It seems very niche and not confident to attend..

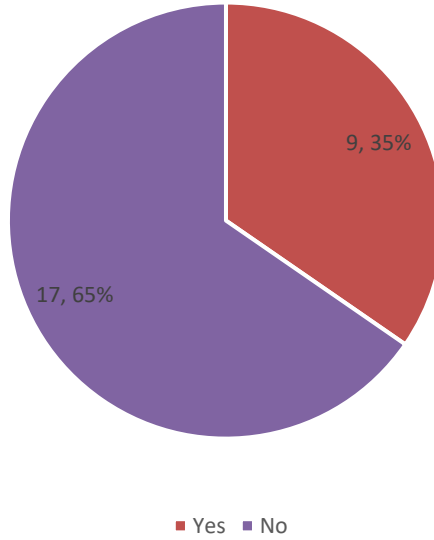
At the moment I feel happy with the support I am receiving, thanks.

- Did not know you could attend online
- I do not have a computer
- Possibly inconvenient as work shifts (on road ambulance PES or in uni)
- The presentations are very helpful and relevant
- Put another block in above: Didn't know such meetings existed
- Very good
- Don't think I would have anything to contribute



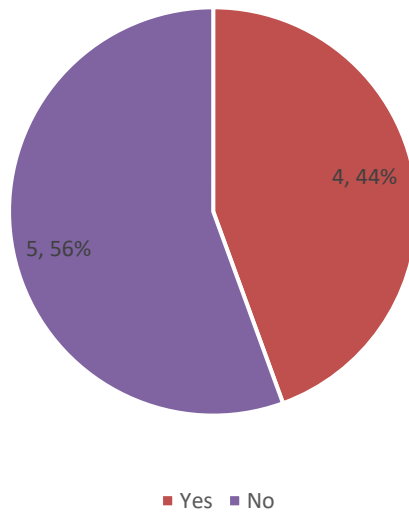
42% are members of the Facebook Support group (21% 2023) which is a large increase since 2023. One reason for this increase could be the text messages sent to all patients after a clinic visit that contain details of CARES team patient support resources.

Q20. There is a twice-weekly online social support for patients & carers on Thursday at 10.00am and Tuesday at 2pm, currently using Teams software. Have you ever heard of it?

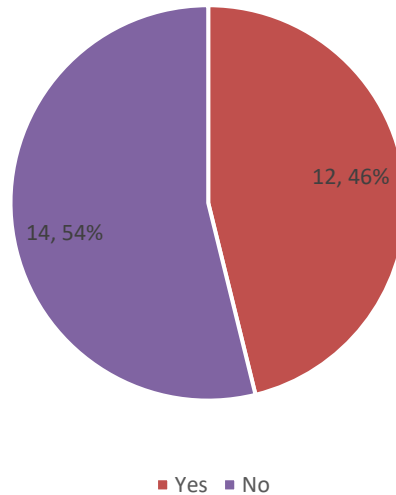


35% have heard of our online social support meetings (28% 2023) which is a significant improvement.

Q20a. Have you ever attended it?



Q21. 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. Would you like to hear more about this?



46% would like to hear more about Telegram (31% 2023). This is presumably due to us promoting this service via text messages after ever clinic.

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

Currently fully satisfied with NAC support including ongoing advice.

Excellent service

I travelled from Kent. Instructions about public transport would be helpful, and where to park at hospital. Very good liaison between x-ray, clinic, blood tests. All very punctual and well integrated.

I am so lucky to have been a patient and have benefitted greatly. I am sorry this last issue occurred where my important video consultation was cancelled. Upset me a lot.

Keep it up

Seems a lot to get my head around but I will make every effort to find out as much information as I can - still awaiting a positive result indicating I have the condition

Very efficient and explained everything

Very satisfied with the care I am receiving.

Just want to say a big THANK YOU for your care over several years. Aspergillosis is not a pleasant disease to have to live with but I have always found all staff sympathetic and helpful.

Had no information, support or contact with anyone (although diagnosed prior to Covid pandemic). Wasn't even given diagnosis verbally - found on hospital discharge letter to GP.

Feeling forgotten and abandoned (to say the least). Not the fault of NAC service but no one else listens (or asks). Thank you for being there for me and others xx

Have been quite happy with the service

Thank you for all your help over the last few years